HANDBOOK ON AUTISM FOR PARENTS:
A GUIDE TO INFORMATION AND SERVICES
IN HUMBOLDT AND DEL NORTE COUNTIES

by

Jay Nord

A Project

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HANDBOOK ON AUTISM FOR PARENTS:
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ABSTRACT

HANDBOOK ON AUTISM FOR PARENTS: A GUIDE TO INFORMATION AND SERVICES IN HUMBOLDT AND DEL NORTE COUNTIES

JAY NORD

This project examines the experiences of children with autism and their families including diagnosis and treatment. Parents, especially those in small rural communities, may find it difficult to access and assess services that are available to them to provide support to their children with autism and to the family as a whole. The content of chapter four is a handbook designed to assist parents and guardians in Humboldt and Del Norte Counties in seeking appropriate services for their children with autism. Content includes information on grief, specialized services, schools, and behavioral techniques that will assist parents in developing a team to support their children with autism and their families.
ACKNOWLEDGEMENTS

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Lastly, I would like to recognize my wonderful wife Tracy, without her love, support, and dinner when I would come home after 8:00 p.m. none of this would be have been possible. To my daughter Lily for quietly doing her “preschool homework” with me so I could focus on my reading and writing and my son Sage for his caring and love.
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CHAPTER ONE
INTRODUCTION

A recent study by the American Academy of Pediatrics suggests that the prevalence in autism could be as high as 1 in 91 children and 1 in 58 boys in the United States. The number of children affected by this disorder continues to rise. If a child is diagnosed with autism, parents need to be informed as to what their options are for support and services.

When a child receives a diagnosis of autism, it can be devastating for parents. Typically, diagnosis will come after parents watch their child’s behavior deteriorate and note that their child has missed developmental benchmarks.

Once a diagnosis is received parents then have to endure the process of compiling a team of professionals to help assist their child in treatment for autism. This process is time consuming and difficult, especially if they do not have the needed information on what services are available to them. The creation of a resource that would offer guidance to families was goal of this project in answer to the question of what would be the content of a handbook designed to assist parents and guardians of children with autism who live in two specific counties in Northern California?

Chapter Two offers a review of the literature in regard to autism including an examination of typical and atypical child development, pervasive developmental disorders, philosophies and methodologies for working with children with autism,
and parents’ role as the primary behavior therapist in working with their children with autism. Chapter Three offers an overview of the methodology used in creating the handbook which is the content of Chapter Four. Finally, Chapter Five provides conclusions, limitations of the research, and implications for future research.
CHAPTER TWO
LITERATURE REVIEW

Introduction

A child’s diagnosis of autism is often devastating for parents. It follows on the heels of disturbing observations of the child’s behavior over time: lack of response when called, lack of desire to be held or consoled, and inappropriate social responses, to name a few. Parents of children diagnosed with autism then begin the arduous task of putting together the team of professionals who will assist in the child’s treatment plans: speech pathologists, occupational therapists, pediatricians, dieticians, and behavioral consultants.

Creating such a support team takes time, sometimes years, time that parents could utilize to become the first responders in assisting their children. However, for parents to begin to intervene on their children’s behalf while awaiting the formation of the support team, they need to know what they themselves can do. Parents can teach their child the skills they need to know in order to enter into preschool or kindergarten and get them ready for when their services do begin. In order to enter most preschools and kindergartens, children need to be able to sit for a period of time, attend to an adult, answer in some form when their name is called, and at least begin the toilet training process.

Parents can begin their behavioral therapy by learning some basic applied behavior analysis techniques. Basic terms such as prompting (assisting the child with the answer), fading (removing prompts), shaping (systematically reinforcing
approximations to the target or desired behavior), chaining (linking small parts of a
skill together to complete a task, like shoe tying), and reinforcing (introducing any
preferred stimuli that will strengthen a behavior) should be learned by parents to
create an effective home behavioral therapy program.

This review of current literature begins with an examination of typical and
atypical child development, including some warning signs of developmental
disorders. The review then examines the range of disorders that fall under the
umbrella of Pervasive Developmental Disorders and reviews various forms of
applied behavior analysis and other therapies that are used to treat children with
autism. This is followed by the roles that parents have in the lives of their children
newly diagnosed with autism and the options available to them.

Typical and Atypical Child Development

This section will provide an overview of typical development of children and
the warning signs for developmental disorders.

Children develop in five major areas: cognitive (problem solving), social and
emotional (interacting with others and self-control), speech and language
(understanding and using language), fine motor skill (using small muscles), and
gross motor (using large muscles) (Roberts & Tamburrini, 1981). Within these five
areas, children reach major milestones throughout their young lives (e.g., learning to
walk, talk, or solve a puzzle) (Roberts & Tamburrini, 1981). When children do not
meet milestones within 6 months of the normal age range in which they should be
met, they may be considered developmentally delayed (Center for Disease Control
and Prevention, 2007). For example, most children learn to walk between 7 and 18 months (Center for Disease Control and Prevention, 2007). If a child is 23 months and still unable to walk, the child could be diagnosed to have a developmental delay (Center for Disease Control and Prevention, 2007). Several warning signs may show up early in children’s development indicating that they may have a developmental delay. These warning signs include specific behaviors such as being unable to stay focused, avoiding or rarely making eye contact, or being aggressive towards others; gross motor difficulties such as exhibiting stiff arms and/or legs or, being clumsier than peers of same age; visual issues such as having difficulty following objects with the eyes, finding and picking up small items, or maintaining eye contact; and hearing difficulties such as being unsuccessful in making sounds or words that peers of the same age are able to make, talking too loudly or too softly, or having difficulty in following directions (Center for Disease Control and Prevention, 2007). More specifically, possible indicators that children may have autism are lack of babbling, pointing, or making any meaningful gestures by age one, not speaking by 16 months, not combining 2 or more words by age two, tending not to respond to their name, and losing previously acquired language and social skills (Center for Disease Control and Prevention, 2007). Other indicators are behavioral, such as lacking eye contact, lacking appropriate play with toys, excessive lining up of items, being attached to a specific item, and lacking social gestures such as smiling (Center for Disease Control and Prevention, 2007).
Pervasive Developmental Disorders

There are five disorders under the Pervasive Development Disorders (PDD) umbrella. They are Childhood Disintegrative Disorder, Rett syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger’s syndrome, and Autism (Center for Disease Control and Prevention, 2007; Kurita, Tomonori & Hirokazu, 2005; Retzlaff, 2007).

One form of PDD is Childhood Disintegrative Disorder, also known as Heller’s Syndrome, Heller’s Dementia, and disintegrative psychosis. Childhood Disintegrative Disorder has similar diagnostic criteria as autism except that children with this diagnosis meet all developmental milestones on time until age two then exhibit marked regression in known skills (Kurita, Tomonori & Hirokazu, 2005). The oldest and most misunderstood form of PDD, Childhood Disintegrative Disorder is second in severity to Rett Syndrome (Kurita, Tomonori & Hirokazu, 2005).

Rett Syndrome is found almost only in girls, causing marked regression before 2 years of age (Kurita, Tomonori & Hirokazu, 2005). It was first diagnosed by a Viennese pediatrician, Andreas Rett, and was found to be a disorder caused by a mutation in a gene found on the X chromosome (Retzlaff, 2007). Because this is a gene mutation disorder, diagnosis can be confirmed by DNA testing (Johnson & Myers, 2007).

Classical Rett syndrome follows four phases. After a seemingly normal prenatal and perinatal (the time period around childbirth, about 28 weeks to the time of birth) history, in the early phase (6–18 months), the child's
development slows down and may even go backward, with avoidance of eye contact and loss of interest in toys. The regression stage (1–4 years) is characterized by dramatic social withdrawal, loss of achieved purposeful hand skills, failing locomotion, communication dysfunction, loss of learned words, frequent screaming spells, cognitive impairment and stereotypic hand movements such as hand wringing or squeezing, and impaired intentional movements or dyspraxia. (Retzlaff, 2007, p. 246)

Another form of PDD is Pervasive Developmental Disorder-Not Otherwise Specified, described as a severe and invasive impairment (Johnson & Myers, 2007). Children diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified have difficulties with reciprocal social situations (Johnson & Myers, 2007). Often this diagnosis is associated with stereotypic behaviors and limited interests or activities, but it does not meet full criteria for Asperger’s Disorder or Autism Spectrum Disorder (Johnson & Myers, 2007).

On the high functioning end of the autism spectrum is Asperger syndrome. Children diagnosed with this disorder

…may have an average or above-average IQ and highly developed verbal skills. Nevertheless, they may communicate poorly, display poor social skills, have few friends, become upset if routines or expectations are violated, have learning difficulties manifesting poor auditory processing, have poor motor skills including handwriting, and may show stereotypical behaviors. (Scheuermann & Webber, 2002, p.11)
Children with Asperger syndrome are in need of various therapies to assist the children and their families in coping with this disability (Scheuermann & Webber, 2002). In the following section, autism, which is within the umbrella of pervasive developmental disorders, will be discussed.

Autism is not a new phenomenon; this disorder has been recorded as far back as 1803 when a Frenchman named Itard found an 11-year-old boy living in the forest who did not have a formal means of communication (Scheuermann & Webber, 2002). Itard later named this boy Victor. It was assumed by Itard that Victor grew up without any human contact (Scheuermann & Webber, 2002). Victor displayed many maladaptive behaviors such as the inability to communicate and the need for objects to be in a particular place. He would exhibit maladaptive behaviors if objects were moved from their original place, and he preferred being around items that comforted him rather than having human contact (Scheuermann & Webber, 2002). The next major advancement in diagnosing autism came in 1943. Dr. Leo Kanner, a psychiatrist at John Hopkins University, not knowing about Itard’s research, listed several features that would identify a child as having a disorder that was at the time called Kanner’s syndrome (Aarons & Gittens, 1992; Johnson & Myers, 2007; Scheuermann & Webber, 2002). Kanner’s syndrome, later called autism, described several key children’s behaviors: an inability to develop relationships with people, a delay in acquisition of language, difficulty using known words in meaningful conversations, delayed echolalia (also called scripting, which is the repeating of statements heard previously that have little or nothing to do with the topic being
discussed), pronominal reversal (e.g., speaking about themselves in the second person), repetitive and/or stereotyped play, inability to handle change, exceptional rote memory, and no physical abnormalities (Aarons & Gittens, 1992). These nine behaviors were later reduced by Dr. Kanner to two essential behaviors: inability to handle change and severe isolation (Aarons & Gittens, 1992).

Today autism currently affects 1 out of 166 children in Europe and North America (Johnson & Myers, 2007; National Institute of Mental Health, 2007). In most cases, autism can be diagnosed in the first 3 years of life (National Institute of Mental Health, 2007). Some children have been diagnosed as early as 18 months, with warning signs showing up soon after birth (National Institute of Mental Health, 2007). Indicators of autism indicate lack of babbling or pointing by age one, lack of speaking by 16 months, loss in social skills, and poor eye contact are all major indicators of the possible presence of autism (National Institute of Mental Health, 2007). It is especially important to look for any regression in skills, plateaus in skills, or lack in skill acquisition (National Institute of Mental Health, 2007). Parents as well as pediatricians need to be educated on autism in order to identify it and begin treatment as soon as possible (National Institute of Mental Health, 2007). “Evidence over the last 15 years indicates that intensive early intervention in optimal educational settings for at least 2 years during the preschool years results in improved outcomes in most children with (autism)” (National Institute of Mental Health, 2007, p.11).
Although communication deficits are among the most marked effects in autism, these children also face many other issues that must be addressed before effective teaching can begin (National Institute of Mental Health, 2007). Children with autism tend to have major sensory deficits that effect their hearing, touch, sight, and even motor control (National Institute of Mental Health, 2007). These lapses in sensory input can keep them from effectively feeling high amounts of pain or cold (National Institute of Mental Health, 2007). Children with autism can fall and break a bone or severely hurt themselves and not ever feel it, yet on the other hand other children scream in pain when their caregivers lightly touch them (National Institute of Mental Health, 2007).

As debilitating as the sensory issues may be in some children with autism, the repetitive or self-stimulating behavior may be the hardest to change (National Institute of Mental Health, 2007; Scheuermann & Webber, 2002). Children will exhibit behaviors such as flapping their hands or arms, rocking back and forth (at times seated or standing), walking on their toes, and lining up items (National Institute of Mental Health, 2007). Some repetitive behaviors may seem innocent enough; however, when children are stopped from completing the cycle of behaviors, a high intensity tantrum may follow (National Institute of Mental Health, 2007). In order to effectively teach children who are perseverating on a motion or object, these behaviors must be eliminated or addressed so that they come out in constructive and appropriate ways (Scheuermann & Webber, 2002). Once the self-stimulatory behavior is addressed, learning will dramatically increase, not only in academics but
in play and social skills as well (Scheuermann & Webber, 2002). The best known way to eliminate a self-stimulatory behavior is to find the function of that behavior (Scheuermann & Webber, 2002). The function may serve as a reinforcer to children (Scheuermann & Webber, 2002). If the function is for tactile input, then children could earn time to play in an area that will give them the sensory input they need (Scheuermann & Webber, 2002). With the self-stimulatory behavior addressed, effective teaching strategies can be put into place (Scheuermann & Webber, 2002).

This section offered an examination of Pervasive Developmental Disorders and their symptoms. The next section discusses the philosophies and resultant methodologies for working with children with autism.

Philosophies and Resultant Methodologies for Working with Children with Autism

Several methodologies have been discovered since Dr. Keller introduced autism to the world (National Institute of Mental Health, 2007). However, the literature is sparse on several treatment options, such as the gluten free/casein free diet, Social Communication-Emotional Regulation-Transactional Support Model (SCERTS), Teaching and Education of Autistic and Related Communication Handicapped Children, and Floor Time. Applied behavior analysis appears to be the most favored treatment option for autism. This section will offer an exploration of various methodologies for working with children with autism including applied behavior analysis.

Teaching and Education of Autistic and Related Communication Handicapped Children (TEACCH) is an organized manner to teach children with
autism and related disorders (Scheuermann & Webber, 2002). Children filter through various workstations that have corresponding letters and/or pictures to the letters or pictures that the teacher has given the student (e.g., Johnny was given the letter A so he travels to workstation A and completes various activities, such as puzzles, worksheets, or games and then is given a second letter and proceeds to the next workstation) (Scheuermann & Webber, 2002). This teaching style has several important elements included in its structure; these include a structured classroom environment, a daily routine that is predictable, and highly structured activities (Johnson & Myers, 2007). This method of teaching has much anecdotal evidence that it is both effective and supported by parents; however, no controlled studies of treatment outcomes have been conducted (Johnson & Myers, 2007).

Dr. Stanley I. Greenspan, Clinical Professor of Psychiatry and Pediatrics at George Washington University Medial School, created a therapy called Floor Time. In this therapy, the adults act as if they do not know what the child wants so as to encourage the child to find ways to communicate (Scheuermann & Webber, 2002). The purpose of Floor Time is to restore the contact with primary caregivers and recreate an interactive relationship (Scheuermann & Webber, 2002). Cognitive and emotional growth is thought to be increased during the interactions with the primary caregiver and child (Johnson & Myers, 2007). It is believed that while rebuilding the relationship the child’s auditory processing, language skills and motor planning will increase (Johnson & Myers, 2007).
“Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and increase communication, learning, and appropriate social behavior” (National Institute of Mental Health, 2007, p. 18). Applied behavior analysis (ABA) is the most widespread theory used to treat children with autism spectrum disorder (Dunlap, Kern, & Worcester, 2001). Educators continuously use ABA to assist in the development of curriculum for children with developmental disorders, including autism, and those who are in general education classrooms (Dunlap, Kern, & Worcester, 2001).

Taking several fundamental features of applied behavior analysis, Dr. O. Ivar Lovaas, a clinical psychologist who is considered to be one of the fathers of applied behavior analysis therapy for autism, created a method of teaching children with autism called The Lovaas Method (Lovaas, 1987). This method was found to be effective in assisting nearly half of the subjects in reaching developmentally appropriate intellectual and educational level (Lovaas, 1987). The Lovaas Method of teaching young children with autism spectrum disorder has had lasting effects on children in both the intellectual and educational realms (McEachin, 1993). The intervention moves with the child’s mastery of skills from teaching basic self help and language skills to teaching nonverbal and verbal imitation skills, and establishing the beginnings of toy play. Once the child has mastered basic tasks, the second stage teaches expressive and early abstract language and interactive play with peers (Lovaas, 1987).
Discrete Trial Teaching (DTT), the techniques upon which the Lovaas Method is based, is highly effective in teaching children with autism to imitate, to comply, and to attend, as well as many other skills (Johnson & Myers, 2007). Discrete Trial Teaching has five main components within only one trial; (1) descriptive stimulus (SD) or an instruction given to the child, (2) if needed, a prompt to elicit the correct response, (3) response (this must be observable and measurable and must come after the SD was given, (4) consequence (this is a stimulus presented directly following the response that will increase or decrease that response in the future), (5) intertrial interval (a predetermined length of time between trials [e.g., 3-5 seconds] which clearly defines one trial from the onset of another trial and gives time for the instructor to record the response and to reinforce appropriate behaviors) (Scheuermann & Webber, 2002). This teaching format is designed to elicit a particular answer when given a particular stimulus (e.g. when shown the word “sun” the child will say “sun”) (Scheuermann & Webber, 2002).

Parents of Children with Autism Spectrum Disorder as the Primary Behavior Therapist

Parents are more often than not their child’s first teacher (McConachie & Diggle, 2005). It is important to have the right tools in order to be most effective (McConachie & Diggle, 2005). Whether a parent is teaching their child by themselves or co-teaching, every advantage a parent can give their child with autism will be helpful (McConachie & Diggle, 2005).
Parents have been co-teaching their children with autism since the 1970s (McConachie & Diggle, 2005). Although the research is lacking in the effectiveness and treatment provided to children with autism by their parents, it does point out that increasing and maintaining skills are important roles parents have played in the education of children with autism (Crockett, Fleming, Doepke, & Stevens, 2007). Parents have been crucial in the role as co-therapists and have made an impact on their children’s lives (McConachie & Diggle, 2005). One benefit of parents and behavioral therapy working as a team is that children can experience an increase in skills learned in one setting that can then be generalized to multiple settings by the parents (e.g., the child learns to expressively label a dog, then is out on a walk with his parents and points and accurately identifies a dog) (McConachie & Diggle, 2005). A side effect of teaching parents behavioral concepts (e.g., prompting, fading, chaining, reinforcement, etc.) is that they are able to utilize these new found concepts in the home and the community (Crockett, Fleming, Doepke, & Stevens, 2007).

This review of the literature examined child development, atypical development, treatment options for children with autism, and finally parents’ roles in working with their children who had been diagnosed with autism. Ultimately, parents’ are the individuals who have primary responsibility for finding and coordinating treatment for their children with autism which led to the question of what would be the content of a handbook designed to assist parents and guardians of children with autism who live in two specific counties in Northern California? The
next chapter offers an explanation of the methodology used in created such a handbook.
CHAPTER THREE
METHODOLOGY

Introduction

Chapter Three outlines the genesis of this project and the events that led me to my interest in the topic. Subsequent sections of this chapter will include a description of the survey I used to assess the need for a handbook on autism for parents and guardians of children with autism, an explanation of the process I used in creating the handbooks, and target populations for its use.

Early Experiences

I began working with children with autism in 1997 while a junior at Humboldt State University in the Psychology Department. As a 1:1 therapist, I worked with the child on various skills (e.g., social, verbal, and academic) to increase their ability to have peer relationships and to decrease problematic behaviors. I worked with two boys for over two years in various settings (e.g., home, community, and school) as they grew up. During this time, I moved to work for Head Start as a Special Needs Aide still working with children with autism. Twelve months after starting to work with Head Start, I graduated from Humboldt State University with my bachelor’s degree in Psychology, and I got a job as a Therapeutic Behavioral Aide for what was then the Humboldt Child Care Council (now Changing Tides Family Services). As funding and clients dried up for that service, I got a full-time job as a Case Manager for Humboldt County Mental Health working at a residential treatment facility for 6 to 17 year olds for three years.
However, I knew in my heart that I needed to be working with the developmentally delayed population, and as a result I became a vendor through the Redwood Coast Regional Center as Behavior Management Assistant for eighteen months. Pacific Child and Family Associates then wanted to open an office in Eureka, and I was hired by them to be a Senior Behavior Therapist and was able to continue to work with a majority of the families that I had when I was a private vendor.

Parents have enough to worry about with having a child with a developmental disorder; they deserve to have one source that meets their needs of finding and accessing local services and activities. Over the last four years, I have talked with many families, and one common topic comes up repeatedly: the lack of a comprehensive local guide to information and services for children with autism. This is what drew me to doing this as a master’s project.

**Needs Assessment**

In order to find out if a need existed within our community for such a handbook, I sent out 103 surveys to families through the Redwood Coast Regional Center. This number of families was what I was given from the Regional Center as the number of families in this area with children under 10 years of age. The surveys were sent out on August 4th, 2009, and by September 14th, I had received 24% of the surveys back. The information gathered in the surveys has steered me in the writing of this project. I have let the parents decide, by the results of the survey, what should be in the handbook. Only 76% of the surveyed parents felt that they had information
on local services for their child with autism. Nearly a quarter of the parents felt they did not have adequate information about what is available to help their child and family, and 100% of the parents stated that a handbook that included information on local services would be helpful to them. Eighty-six percent of respondents stated they were not provided with ample information about services when their child was diagnosed. I asked parents if they had knowledge of basic behavioral techniques, and 86% responded that they did. However, over 90% responded that additional information about behavioral techniques would be very important, as well as nearly 90% of the respondents stating that information on local services and support groups was very important. Table 3.1 below shows the content of the survey and the predominant response from parents.

Table 3.1: *Survey Questions and Parents’ Predominant Response*

<table>
<thead>
<tr>
<th>Survey Questions</th>
<th>Predominant response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Do you have information on local services for individuals with autism?</td>
<td>Yes</td>
</tr>
<tr>
<td>2: Would a handbook that includes information about services in your area be helpful to you?</td>
<td>Yes</td>
</tr>
<tr>
<td>3: Do you feel you were provided with ample information about all services that are locally available?</td>
<td>No</td>
</tr>
<tr>
<td>4: Do you have knowledge of basic behavioral techniques?</td>
<td>Yes</td>
</tr>
<tr>
<td>5: Are you currently receiving behavioral services for your child with autism?</td>
<td>Yes</td>
</tr>
<tr>
<td>6: Would information on educational services and laws be helpful to you if included?</td>
<td>Yes</td>
</tr>
</tbody>
</table>
From the information gathered in the survey, I found that the families were not informed of all services that are available to them when their child was diagnosed. The survey data were helpful in determining what other information the families would find useful if this handbook existed. From the survey, I was able to conclude that a handbook would be a useful tool for parents, that information on behavioral techniques and educational services and laws would be helpful, and that some basic teaching strategies would be useful in helping out their children with autism.

Once I compiled the data from the surveys that were returned, I sought to gain what information I could from the various agencies in our area that provide services to children with special needs. I was able to dilute the information down to a form that would be manageable and accessible for parents. First, I used my own knowledge of what services were available to children with autism to begin the
process of listing service providers. While listing the providers, I realized that some sort of order was needed to make it more efficient for parents to access the services they need or would like to obtain.

As someone who works within the autism profession, I was able to find out additional information of which initially I had not been aware. For instance, I assumed there was a local agency that provided respite services to families in Del Norte County. That assumption was not accurate; from the information I was able to attain, there aren’t any agencies providing true respite services. While researching the services that are available in our area, I was able to acquire much more information about the different agencies that provide services to families. Having all of this information in one spot, I hope, will greatly help a family with a newly diagnosed child.
CHAPTER FOUR

CONTENT

The following handbook for parents of children with autism forms the content of Chapter Four.
HANDBOOK ON AUTISM FOR PARENTS:
A GUIDE TO INFORMATION AND SERVICES
IN HUMBOLDT AND DEL NORTE COUNTIES

Introduction

It isn’t easy being a parent. It gets more difficult when your child has a developmental disorder such as autism. The following information has been compiled in an effort to make some of your life a little easier in accessing local services, support groups, and activities that you can do with your family. I have also included information about some actions you can take that may help in making the transitions that occur in the first few years somewhat more manageable and attainable. As a parent, you will do the best you can with the knowledge you have. I am hoping that after reading this, you will be a more informed parent than you were before and have more knowledge about how to help your child succeed in life.

Parents may be struck with grief when someone has given their child a diagnosis of autism. The first chapter will provide ways to assist you in dealing with that grief and the other emotions that may follow such a diagnosis. The chapter will discuss the stages of grief, the ways they may relate to you, and the parent support groups that are available in our area.

The next chapter will go over the services that can be available to you through the Redwood Coast Regional Center. Services included are respite, behavioral respite, and behavioral intervention services.
Chapter three gives a brief introduction to applied behavioral analysis and several of the components that are under the umbrella of applied behavioral analysis (e.g. reinforcement, shaping, and extinction).

The following chapter will delineate the various schools that service children with special needs and information on where to access education laws. This may help in locating the right school for your child from preschool through high school.

The last chapter will include various informational web sites, phone numbers, and information about doctors who have experience with children with special needs or autism.
Chapter 1

Grief: The Loss of a Dream

Some parents have told me that when their child was diagnosed, it was somewhat like the child they thought they were going to have in their life had died. When your child is born, you may have had hopes and dreams for your child. With a diagnosis of autism, those dreams may be more difficult for them to attain.

According to Dr. Elizabeth Kubler-Ross (Kubler-Ross, 1969) people go through 5 identified stages during times of loss. I have included an overview of these stages and the ways they may affect families that have children diagnosed with autism. The stages are discussed in the table below.
<table>
<thead>
<tr>
<th>Stage</th>
<th>Dr. Kubler-Ross’s definition</th>
<th>How it may apply to a family when a child has been diagnosed with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td>At first, we tend to deny the loss has taken place and may withdraw from our usual social contacts. This stage may last a few moments or longer.</td>
<td>This can often occur even before the diagnosis. “There isn’t anything wrong with my child.” The sooner that you can come to grips that this is real, the sooner your child can start to access the available recourses that are available in the community.</td>
</tr>
<tr>
<td>Anger</td>
<td>The grieving person may then be furious at the person who inflicted the hurt (even if she's dead), or at the world, for letting it happen. He may be angry with himself for letting the event take place, even if, realistically, nothing could have stopped it.</td>
<td>Anger may manifest itself in ways that may be detrimental to assisting a child with autism. Problematic behaviors that children with autism can exhibit can compound the anger. This can be the stage in which some families start to attempt to access assistance from professionals.</td>
</tr>
<tr>
<td>Bargaining</td>
<td>Now the grieving person may make bargains with God, asking, &quot;If I do this, will you take away the loss?&quot;</td>
<td>This may take place in the same way that Dr. Kubler-Ross’ definition. However, the bargaining may transfer to people that end up working with your child.</td>
</tr>
<tr>
<td>Depression</td>
<td>The person feels numb, although anger and sadness may remain underneath.</td>
<td>Unfortunately, some people can get stuck in this stage. Some agencies that provide behavioral services also provide counseling services to help families.</td>
</tr>
<tr>
<td>Acceptance</td>
<td>This is when the anger, sadness, and mourning have tapered off. The person simply accepts the reality of the loss.</td>
<td>Once you are able to accept that your child has autism, you can rationally set up goals that will best help your child grow and increase skills in all areas.</td>
</tr>
</tbody>
</table>
Getting through the stages will help you come to grips with the diagnosis. Some parents find it helpful to join support groups to help them get through the stages and so that they don’t feel alone in having a child with autism. Unfortunately, there are few support groups in Humboldt and Del Norte counties. Joining the ones that are available may be helpful in getting to meet other people in the area who are going through or have gone through the same things that you are. I have compiled the information on the only support group that is currently active and the times, days, and contact information in Table 2.

*Table 2: Local Support Groups*

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Day/Time</th>
<th>Contact Info</th>
<th>Description of Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAAN Network</td>
<td>First Tuesday of each month at Bounce-A-Palooza</td>
<td>(707) 498-9535</td>
<td>We are parents of children who have been diagnosed with Autism in the Humboldt County, California area. Our group is dedicated to finding new and better ways to help the education system adapt to the growing and changing needs of the autistic child. Our group of mothers, fathers, and families are dedicated to finding a way to give these children the opportunities to succeed in new and extraordinary ways. Please join in helping us prepare the education system for these children to learn and grow as would any other child.</td>
</tr>
</tbody>
</table>
Chapter 2
What Can I Do? Who Can Help?

Once your child is diagnosed with autism or related disorder, you as a parent have to figure out what types of services are right for your child and your family. There are several different types of services that are available in Humboldt and Del Norte Counties. The first step to receiving any sort of services is to become a client of the Redwood Coast Regional Center. The RCRC serves the counties of Humboldt, Del Norte, Mendocino, and Lake. At the RCRC, they can help refer you to other doctors, if needed, acquire services (e.g. behavioral, respite, etc.) and assist with needs your family may have (e.g. nutrition, diapers, etc.). As a client of the RCRC, your assigned service coordinator will meet with you to assess your child’s needs and assist you with finding out which of the various services that are provided in Humboldt and Del Norte Counties are right for you and your family. Over the course of this chapter I will explain what various services are available.

**Respite Services**

One service that is used by many families is respite services. Respite means that you as the parent get reprieve from the daily tasks that you are expected to do, some time to let a qualified person to be with your child, and give them additional 1 to 1 attention. The two agencies in our area that provides respite services are Changing Tides Family Services and Humboldt County Action & Resource Center (HCAR).
Respite is much like hiring a babysitter. The difference between you hiring someone and a respite worker is that the latter has been screened for illegal activity, has first-aid and CPR qualifications, and often has previous experience with a child who has an autism diagnosis. Respite services are available so that you, the parent, can take some time off but still feel that your child is being cared for by someone who is more qualified/trained than the neighborhood babysitter. This service is set up to be a chance for the family to receive some time to get things done without bringing their child with special needs along (e.g., grocery shopping or a date with your spouse). This time is also spent recharging yourself as a parent so that you can continue to be the best parent you can to your child. The respite team can help your family work on various goals to increase skills (e.g. self-help) or decrease problematic behaviors (e.g. yelling). During respite times, the provider may work on goals ranging from going to the store to tying shoes. If assigned, a behavioral analyst will assist the team in developing the goals that the respite provider will be working on while with your child.

*Independent Behavior Analysts*

Behavior analysts that become a vendor (think of them as independent contractors paid by the Redwood Coast Regional Center) through the Redwood Coast Regional Center are assigned to children receiving behavioral respite services through either HCAR or Changing Tided Family Services. They work with the family to set up behavioral and skill goals to work on with the behavior respite
workers. The behavior analysts who become a vendor of the Regional Center are independent contractors and not part of any organization or agency.

**Behavioral Intervention Services**

There are three agencies that provide behavioral intervention services to Humboldt and Del Norte Counties: Multiplicity Therapeutic Services, Pacific Child & Family Associates (PCFA) and Quality Behavioral Outcomes (QBO).

**Multiplicity Therapeutic Services (the following information was provided by MTS)**

“Although Multiplicity Therapeutic Services (MTS) will be acknowledging in March of 2008 only its first anniversary as a Redwood Coast Regional Center vendor, it has actually taken over 30 years of experience in working with individuals with developmental disabilities to get to this celebrated point in time. MTS’s time and efforts relative to providing services to individuals with developmental concerns and their families has included working with a number of regional centers throughout Northern California and in many specialized domains of service provision and advocacy including; the development and supervision of supportive living programs, development and directing of behavioral crisis services, coordination of early intervention services, clinical and administrative oversight of behavioral and skill based day programs, residential (4i) program development and operation, behavioral assessment and intervention services for individuals and their families, socialization and recreational therapy program design, development and operation, early intervention skills assessment and support, therapeutic behavioral
support for individuals with mental health concerns, and extensive background in providing training to many outside agencies covering most facets of behavioral and developmental assessment, intervention, and skill acquisition methodologies. MTS’s experience has also included many years of providing advocacy including time spent on the board of directors of the Association of Retarded Citizens (ARC).

“MTS’s stated mission is to continue to provide the highest quality of professional behavioral and skill acquisition services to the individuals (children and adults) and agencies they serve. As you come to know MTS you will find that their organization prides itself on the quality of care delivered to those in need. MTS’s staff is comprised of individuals whom possess Bachelors as well as Masters levels of education in the fields of Education, Social Welfare, and Psychology. MTS staff are required to be able to demonstrate advanced skills and proficiency in the area of attending to the behavioral challenges and skill deficits of those we have been charged to assist and are strong proponents of not only community inclusion but proponents of the individuation process as well. The fact that MTS staff come from a variety of educational, social, and cultural backgrounds affords MTS an opportunity to offer a diverse service that can address many of the complexities that regional center families possess. MTS is an organization that prides itself on maintaining a person-centered approach to providing services. MTS’s philosophy is Humanistic, which in the form of action includes providing unconditional care to others, the highest of respect for personal choice and an understanding of the responsibilities
that go with choice making. Although much of MTS’s professional orientation is within the positivist and empirical paradigms within the field of Psychology, as a means of maintaining a sense of balance and relating to the diverse needs and character styles of our consumers and families we are best described as eclectic in our approach with others. MTS staff are required to posses experience working with a multitude of individuals including those whom not only possess developmental, and autistic spectrum challenges but mental health concerns as well. MTS’s collective experience includes working with children and adults whom possess a variety of behavioral challenges and skill deficits that have affected and impacted not only their community participation and accessibility but educational opportunities, inter-personal growth, vocational accessibility, social participation and the entitlement that goes with being a citizen of the communities the reside in as well.

“We have an extensive understanding of the rights that all individuals have to reside and prosper in the least restrictive environment in all facets of their lives and of the right to access not only their community but their world as well. As an organization we understand the concept of personal and cultural respect and of the responsibility we have as an organization to support individuals in realizing their individual objectives and choices. MTS’s work with people has and will continue to put a person’s rights for self-determination at the forefront of their practice of caring for and collaboration with others. MTS understands that they have been given an incredible responsibility to assist individuals reach their fullest potential and to
provide assistance as needed to help others reach their hopes, dreams, and wishes and goals in the present and in the future as well.”

**Pacific Child & Family Associates (PCFA) (Information provides by PCFA)**

“Pacific Child and Family Associates opened its doors in 1988 as the **Verdugo Hills Psychotherapy Center**, a name we changed in 2002 to reflect the wide geographic area we now serve.

“In 1988 we provided all of our services in our offices and on school sites in Glendale, California. We first expanded to Orange County, and then opened offices in the San Francisco Bay Area. We opened our Redwood Coast office in Eureka in 2005, and our Fresno office in 2006. We currently have eleven locations in California, New Mexico, and Texas, and continue to expand our reach. Our programs for children with autism and related disorders are comprehensive, and designed specifically to meet each child’s needs.

**“Our Principals and Staff:**

*Ira Heilveil, Ph.D.* has worked with children with autism and related disorders for more than 20 years. He received his master's degree in psychology from Murray State University in Kentucky in 1977 and his doctorate in psychology from the California School of Professional Psychology in 1980. Dr. Heilveil is the author of *When Families Feud: Understanding and Resolving Family Conflict* (Perigee/Berkley) and *Video in Mental Health Practice* as well as many professional articles and presentations. He is assistant clinical professor of psychiatry at UCLA
School of Medicine.

“Cara Entz, M.A., MFT began her career in autism at UCLA as an undergraduate through studies with Dr. Ivar Lovaas. After her graduation with a BA in Psychology, she co-led his Autism Project for one year prior to entering graduate school. As a therapist, her experience has included individual, family and group therapy in the areas of depression, oppositional defiant disorder, severe emotional disturbance, child abuse, and adjustment disorder.

“Ms. Entz was instrumental in the development of the first Deaf Foster Care Program in the United States, as well as the creation and implementation of an Intensive Treatment Foster Care program to provide transition into family settings for more severely affected children. She joined Pacific Child and Family Associates as a consultant in 1998, and became Clinical Director in 2002. She is a licensed marriage and family therapist, and a board certified behavior analyst.

“Our Behavior Therapists:

‘Pacific Child and Family Associates' staff members undergo rigorous training, both prior to seeing children and on the job. Each staff member receives individual supervision while working with children; besides the introductory training, overlap sessions and supervision, staff receive ongoing continuing education and attend team meetings.

“Staff members with over two years of experience, and who stand out as exceptional therapists, are promoted to the position of senior therapist. Senior
therapists receive additional training, and the position carries additional responsibilities.

“**Our Supervisors:**

“Each family is assigned a supervisor, who designs, coordinates, and modifies treatment programs regularly. Our supervisors typically possess a master’s degree in a relevant field as well as experience as senior therapists. They are selected less for their credentials than for their experience and success as senior therapists. All of our supervisors have demonstrated their success in their field, either by coming up through the ranks within our own organization, or by attaining their expertise elsewhere.

“When they are hired from outside of the organization, supervisors undergo a trial period in which their skills are evaluated in order to determine the extent to which their skills match the philosophy of the organization, and are up to the level we require of our supervisors. Our supervisors all receive monthly in-service training on a variety of topics relevant to developmental disabilities, and are given a conference allowance for attending outside workshops and trainings.

While we strive to obtain consistency among our supervisors, we also encourage their use of their own creative solutions to problems. Our supervisors all report to the Clinical Director, and meet with each other regularly to consult on difficult problems.
“Our Program

Pacific Child and Family Associates is dedicated to providing the highest quality services to children with developmental disabilities, particularly those along the autism spectrum. All of our services are based on a foundation of respect for the dignity of the child, and we strive to create a positive, loving atmosphere. We work collaboratively with the family, and consider the family both team members and co-therapists whenever possible.

“Our methods are grounded in an appreciation for the most current research. Working from within the broad spectrum of applied behavior analytic techniques, we will employ empirically validated approaches as needed by the individual. As an essential component to our collaborative approach, we foster cooperation between service providers, funding sources and other agencies.

“The Details

Our services begin with a review of previous assessments. This includes medical diagnostic evaluations, assessments performed by psychologists, speech and language therapists, IEPs, Regional Centers, or school district personnel. When prior assessments appear inadequate, we will recommend the assessments needed prior to our implementing services, or if our services appear beneficial, we will conduct our own assessment as an integral part of the beginning phase of treatment.

“We will also be happy to review any prior services delivered, and continue a program begun by another provider if the methods and philosophy are similar.
“Programs will often start with a compliance phase, in which children learn the most basic skills required to learn and to benefit from further interventions. Discrete trial methods are primarily methods designed to teach children to acquire skills, as well as to learn how to learn. Complex skills are broken down into their smallest components, and our therapists patiently teach these component skills to our children using reinforcements that are meaningful to each child. While reinforcers vary, they typically include lots of warmth, praise, and other social reinforcers. As children master each individual step, they experience success and move along to the next step in the curriculum. Each step is based on successfully completing the previous steps, although we often carefully re-introduce previously mastered steps in order for children to sustain the growth that they have made (and continue feeling successful).

“The curriculum includes skills required for success in school, social relationships, and the acquisition of language. There is also an emphasis placed on self-help skills. Time spent at the table is punctuated by plenty of breaks in which children play, and are given opportunities to express themselves freely and in the context of a kind, supportive environment. Generalization of skills learned at the table is built into the discrete trial curriculum, and is assured in a variety of ways.

“Shadow Aides

“We also provide one-on-one shadow aides in the classroom setting. While discrete trial approaches mentioned above are excellent for developing skills and generalizing them to as many social spheres as possible, our ultimate goal is to return
a child to as normative (least restrictive) an environment as possible. This often requires an aide to help a child adjust to the demands of a classroom environment. Aides work with specific academic and behavioral goals, keep logs of progress, and work in collaboration with services provided in the home.

“Families who receive our services may also be eligible to receive supportive individual counseling, parent training and attend support groups.”

Quality Behavioral Outcomes (This information was gathered from QBO’s website)

“Philosophy

“We respect the uniqueness of each child; their thoughts, feelings and actions; and the importance of their family, school and community relationships. We acknowledge the values and strengths of these children, their families, and others who teach and support them. We recognize the need, and are committed, to work collaboratively within the child’s environment and supportive relationships to effectively nurture human growth, improve behavioral functioning, and enhance the life quality of each child.”

“Mission

“QBO works to create genuine partnerships with children, youth, families, schools, organizations and professionals to provide the highest possible standard of behavioral health care, education, and consultation. Our goals are to 1) achieve positive behavioral outcomes for children and youth; 2) increase the knowledge and skills of individuals, teams, and organizations to develop and maintain healthy
behaviors; 3) enable our partners to reduce potential problems and successfully address future challenges; and 4) obtain these quality outcomes in an efficient and effective manner.

“Objectives

“We will partner with the individual and team to achieve the following measurable outcomes:

- A decrease in destructive, disruptive, and unhealthy behaviors.
- An increase in healthy, productive behaviors.
- An increase in the child/youth’s personal, communication, social, recreational, academic, problem-solving and other life skills.
- An increase in the child/youth’s sense of self-worth, happiness, and success.
- An increase in the team’s ability to encourage, support, and reinforce healthy behaviors and choices.
- Reports of satisfaction from all partners.

“Core Values

“We at QBO believe in and implement the following core values:

- We respect the culture, values, and strengths of each child, youth, family and system.
- We value the power of genuine partnerships and encourages collaboration between families, teachers, professionals, schools, organizations and community members.
• We are committed to **empowering** children, youth, and partners, through **knowledge and skills**, to **prevent** potential problems and to successfully **address** future challenges.

• We utilize **behavior and learning principles** together with **functional, strengths-based, and systemic approaches** to provide **practical and effective services**.

• We work to achieve **cost-effective, measurable results**.

• We ensure **accountability** through continuous **monitoring and evaluation** of its services.

• We promote **high quality services** by careful selection, training, monitoring and support of its **valued personnel**.

• We are committed to the ongoing **training and professional development** of QBO personnel.”
The following is an overview of the various services offered by the three agencies:

<table>
<thead>
<tr>
<th>Methods Used to Increase Skills &amp; Types of Services Available</th>
<th>Multiplicity Therapeutic Services</th>
<th>Pacific Child &amp; Family Associates</th>
<th>Quality Behavioral Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applied Behavioral Analysis</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Discrete Trial Teaching</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Natural Language Paradigm</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Play Based Teaching Strategies</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Consultation to Other Agencies/Schools</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Intensive Behavioral Services</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Functional Behavioral Assessments</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Educational Advocacy</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling Outings</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Counseling Services</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>In-Home Behavioral Consultation</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Early Intensive Behavioral Interventions</td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Intensive Behavioral Supports</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Language Acquisition</td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>1:1 Services</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Social Skills Development</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Skill Training</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Task Analysis</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Community Trainings</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Overnight Care</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Training/Support</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Chapter 3
Behavioral Techniques to use at Home

Lags in time can occur between when your child is diagnosed with autism to when services can get started. Because of that, I wanted to include a section of this handbook on ways you, as the parent, can begin to make some long lasting changes in your child’s behavior. I will provide you with ways to communicate with your child with autism that are based on current research material in the field of applied behavioral analysis.

REINFORCEMENT

The basis of some human actions relies on whether or not we are reinforced for those actions. **Positive reinforcement** occurs when a consequence to a behavior results in an increase in the likelihood of the behavior occurring again in the future under similar circumstances. In other words, if we are positively reinforced for doing a specific behavior, we will most likely do it again. For example, when we come to work and do our job, we receive a paycheck. **Positive reinforcement** refers to the occurrence of a preferred consequence that follows a behavior. Some advantages to using positive reinforcement are that it can be used on a wide variety of behaviors and can be used to produce new (desired) behaviors.

An example of how to use positive reinforcement is when children finish their homework and are able to play their Wii.
On the other end of the reinforcement spectrum is negative reinforcement. **Negative reinforcement** occurs when the behavior removes a stimulus (usually an aversive stimulus). In other words negative reinforcement occurs when an unwanted stimulus is taken away which then reinforces your behavior. An example of negative reinforcement is coming home to a cold house to find you left the window open. You close the window, which stops the cold air coming in, and the house begins to warm. Remember that this is not a punishment procedure and for certain events this may be more effective that positive reinforcement.

**Advantages and Disadvantages of Negative Reinforcement**

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase future occurrence of desired behavior</td>
<td>Negative reinforcement can be used too often, and individuals will avoid situations in which the aversive stimuli is presented</td>
</tr>
<tr>
<td>Can be used for multiple behaviors in multiple settings</td>
<td>Somewhat limited in the settings that it can be used in</td>
</tr>
<tr>
<td>Can be used with a great variety of reinforcers</td>
<td>Somewhat limited in the stimuli that can be used as negative reinforcement</td>
</tr>
</tbody>
</table>

*Note: the disadvantages can be avoided by using a combination of positive and negative reinforcement.*

The items, activities, acts, feelings, etc., that make positive reinforcement work so well are called **reinforcers**. A reinforcer is the consequence that results in the increase in the desired behavior. Reinforcers will affect the behavior that **immediately** precedes them. A reinforcer will also strengthen wanted and unwanted behaviors. There are three types of reinforcers; they are primary, secondary, and generalized. Think of **primary** reinforcers as items that are naturally reinforcing to
us as humans, such as food, shelter, water, etc. They do not need to be paired, or presented at the same time, with other things for us to like them. **Secondary** reinforcers can be thought of as items the help us to access the primary reinforcers or are paired with primary reinforcers at the time of delivery. Finally, a **generalized** reinforcer is a conditioned reinforcer that has been previously paired with many other reinforcers (e.g. such as tokens or money).

It is important to utilize that so-called big-ticket items (e.g., favorite book, food, activities) for the activities that are more difficult. I recommend having a bag of tricks when you begin to increase the demands or number of instructions that are put on your child. When you are able find those highly motivating items for children to work for or when a higher level of responses is needed, it will help to build independence in that activity. Remember to vary the items that are used to reinforce, or keep the reinforcers small enough so that you avoid satiation. Satiation occurs when reinforcers lose their value by being used over and over again or are available for free access. It is like giving people free access to their favorite food, and then telling them to go clean their room, and they can have more of their favorite food. Most likely that won’t work, for obvious reasons.

To avoid satiation you can vary the reinforcers. Conducting a reinforcer assessment will help you to find out what is reinforcing to your child. This can be done by asking them if they are able to communicate, or by asking yourself or other significant people in the children’s life what they like to play with or eat, what
activities they like to do, etc. If that doesn’t work, you can just start to try various items (e.g. food, toys and games) by giving them free access to items and writing down what they prefer.

There are several schedules of reinforcement. The three that I feel will work the best for you in the home setting are continuous reinforcement, intermediated reinforcement and extinction. **Continuous reinforcement** (CRF) is when an individual is reinforced for each occurrence of the desired behavior. An example of continuous reinforcement is each time that Sally raises her hand and waits to be called she earns an extra minute of computer time at the end of the day. Once a new behavior has been learned, then you can move to intermittent reinforcement. **Intermittent Reinforcement** is when a reinforcer is delivered on a schedule of reinforcement that is **not** continuous. An example is slot machines: the person placing money into the machine never knows when the payout will occur which will increase the odds that additional money will be put into the machine in hopes of a large payout occurring. Intermittent reinforcement is the strongest level of reinforcement and can be used to maintain the continuation of learned behaviors. The final schedule of reinforcement is one that provides no reinforcement at all. It is called **extinction**, and it occurs when no instances of the behavior are reinforced. Another example is when Sally whines for what she wants when she knows how to use her words to ask for her needs and wants. Extinction could be used to not
reinforce the whining behavior and then when Sally uses her words, reinforce her by giving her the desired item.

There are a couple instances where the extinction procedure is not recommended. One instance is when your child or others are in danger of being injured. Secondly, if all people working with the child don’t feel that they can ignore the behavior at all times, then this procedure will not work. If the extinction procedure is be utilized appropriately, then an extinction burst may occur before the behavior gets better. An extinction burst is when a behavior that was previously being reinforced is no longer receiving reinforcement. The individual will most likely increase the topography (what it looks like including the intensity, duration, and frequency) of the behavior to attempt to receive reinforcement. When the extinction burst occurs, it is very important to continue the extinction procedures and ignore and redirect the behaviors to more appropriate behaviors.

FUNCTIONS OF BEHAVIORS

The only way to know why a behavior is occurring is to find the function of that behavior. The function of a behavior is the reinforcement or reinforcer that has been maintaining a behavior or causing the behavior to increase. An example of this is when a child who is supposed to be going to sleep tells his mother that his stomach hurts. His mother lets him get up and cuddle on the couch with her. and he falls asleep. What do you think was the function of Billy’s behavior? The function of his behavior was attention. The child wanted his mother’s attention so he told her that
his stomach hurt so he could be with her. There are four major functions of behaviors; they can be remembered by the acronym S.E.A.T.

<table>
<thead>
<tr>
<th>S</th>
<th>Sensory Stimulation</th>
<th>This can come from verbal, visual, audible, and physical sensory stimulation. An example of this could be a child engaging in self-injurious behavior.</th>
</tr>
</thead>
<tbody>
<tr>
<td>E</td>
<td>Escape or Avoidance</td>
<td>An example is when the child exhibits behaviors to get out of doing a non-preferred activity.</td>
</tr>
<tr>
<td>A</td>
<td>Attention</td>
<td>Possible functions are that the child is getting praise, social attention, physical interactions (e.g. tickles) or even likes the reaction when exhibiting the behavior.</td>
</tr>
<tr>
<td>T</td>
<td>Tangible items or activities</td>
<td>This can be that the child wants to gain access to toys, food or other items.</td>
</tr>
</tbody>
</table>

In order to find the function of behaviors, you need to collect data for couple weeks to a month. This data collection period is called a baseline. During baseline, it is important to clearly describe the antecedents (A) to the behaviors, the behavior (B) itself, and the consequences (C) that are present after the behavior occurs. ABC data will allow you to find the most likely antecedents to the behaviors of concern, identify what consequences may be maintaining the behaviors and an idea of the frequency, duration and intensity of the behaviors. Here is an example of how to collect ABC data;
### ABC Data Chart

<table>
<thead>
<tr>
<th>Date, Time &amp; Person Collecting Data</th>
<th>(A) Antecedent</th>
<th>(B) Behavior</th>
<th>(C) Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>09/09/09 1:43pm Jay</td>
<td>Sammy led me to the fridge.</td>
<td>Pointed at the fridge and grunted.</td>
<td>I got him some juice.</td>
</tr>
</tbody>
</table>

According to the data for the above example, the function of Sammy’s behavior of pointing and grunting was to access a tangible item, in this case juice.

Not all data that you collect with be this plain to see. That is why keeping baseline data for so long is necessary.
# Chapter 4

## Schools and Educational Information

### Humboldt County

#### Arcata Preschools
- Rainbow Bridge Preschool  
  (707) 825-7447
- Arcata Children’s Center  
  (707) 822-1423
- Northcoast Children’s Center  
  Head Start Preschools  
  (707) 822-7206
- Saint Mary’s Catholic School  
  (707) 822-3877
- Humboldt Educare Preschool  
  (707) 822-6447
- The Arcata Christian School  
  (707) 822-5986
- Children of the Redwoods Preschool  
  (707) 822-0167
- Little Learners Preschool  
  (707) 822-4435
- ABC Preschool  
  (707) 826-7675
- Mad River Montessori Preschool  
  (707) 822-4027
- Humboldt State University Foundation  
  (707) 826-4189
- Arcata Children’s Center  
  (707) 822-4618

#### Blue Lake
- Blue Lake Preschool  
  (707) 668-5679

#### Eureka Preschool
- Little People’s Corner  
  (707) 445-0339
- St. Bernard Catholic School  
  (707) 443-2735
- Teacher’s Pet Educational Preschool  
  (707) 442-4877
- Little Angels Preschool  
  (707) 443-9544
- Woodside Preschool  
  (707) 445-9132
- Play and Learn Preschool  
  (707) 442-4855
- Winzler Children’s Center  
  (707) 441-2498

#### Mckinleyville Preschools
- Noah’s Ark Christian Preschool  
  (707) 839-2476
- Strongbridge Montessori School  
  (707) 845-5173
- Rooney-Mckinleyville Children’s Center  
  (707) 839-1120
- Dow’s Prairie Children’s Center  
  (707) 839-2170

#### Fortuna Preschools
- Great Beginnings Preschool  
  (707) 725-9136
- Prime Montessori School  
  (707) 725-1997
- Head Start-Fortuna Site  
  (707) 725-3220

#### Trinidad Preschools
- Salmonberry Farm Preschool  
  (707) 677-0477
- Moonstone Child Development
Center
(707) 677-0648

**Loleta Preschools**
- Loleta Preschool
  733-5705

**Willow Creek Preschools**
- Willow Creek
  Head Start
  (530) 629-2283

**Del Norte County**

**Crescent City**
- Grace Lutheran Preschool
  Day Care Center
  (707) 464-7604
- Crescent City
  Head Start
  (707) 464-1224
- Crescent City - NCS – Del Norte Office
  (707) 464-6936
- Crescent City - NCS Infant & Toddler Center
  (707) 465-4807
- Pine Grove HS & Early Head Start
  (707) 465-6737

**Smith River**
- Smith River HS & Preschool
  (707) 487-0216

**ALPHABETICAL LISTING OF COUNTY SCHOOLS**

(All area codes are 707 unless otherwise indicated)

- Academy of the Redwoods
  476-4203
- Agnes J. Johnson
  946-2347
- Alice Birney
  441-2495
- Ambrosini, Norman G.
  725-4688
- Arcata School District
  822-0351
- Arcata Elementary School
  822-4858
- Arcata High
  825-2400
- Big Lagoon
  677-3688
- Blue Lake Union
  668-5674
- Bridgeville
  777-3311
- Captain John Continuation High
  (530) 625-5600
- Casterlin
  926-5402
- Catherine L. Zane Middle School
  441-2470
- College of the Redwoods
  476-4100
- Cuddeback Union
  768-3372
- Cutten School District
  441-3900
- Cutten School
  441-3900
- Dow’s Prairie
  839-1558
- Eagle Prairie Elementary
  764-5694
- East High
  725-1673
- Ettersburg School
  986-7677
- Eureka Adult School
  441-2448
- Eureka Unified School District
  441-2400
- Eureka Senior High
  441-2508
- Ferndale Unified School District
  786-5900
- Ferndale Elementary
  786-5300
- Ferndale High
  786-5900
- Fieldbrook
  839-3201
- Fortuna Adult School
  725-4482
- Fortuna Union Elementary (Dist. Office)
  725-2293
- Fortuna Middle School
  725-3415
- Fortuna Union High (Dist. Office)
  725-4461
- Fortuna Union High School
  725-4461
- Freshwater
  442-2969
- Garfield
  442-5471
- Glen Paul School
  445-7068
- Grant
  441-2552
- Green Point
  668-5921
- Honeydew
  629-3230
- Hoopa Valley Elementary
  (530) 625-5600
- Hoopa Valley High
  (530) 625-5600
- Humboldt Bay
• Northcoast Preparatory & Performing Arts Academy Charter School 822-0861

Arcata Elementary District Charter Schools
• Coastal Grove Charter School 825-8804
• Fuente Nueva Charter School 822-3348
• Union Street Charter School 822-4845

CHARTER SCHOOLS
(All area codes are 707 unless otherwise indicated)
• Freshwater Charter School 442-2969
• Jacoby Creek Charter School District 822-4896

Loleta School District Charter Schools
• Pacific View Charter School 269-9490

Mattole Valley Charter Schools 629-3634
• Beginnings Site 923-3617

• Campus House 822-5661
• Cutten Resource Center 476-8406
• Laurel Tree 822-5626
• North Coast Learning Academy 442-6200
• Redway Site 923-9532
• Willowbrook Learning Center 725-7971

Northern Humboldt

Union High School District Charter School
• Six Rivers Charter High School 825-2428

Pacific Union School District Charter School
• Trillium Charter School 822-4721

South Bay Union School District Charter School
• Alder Grove Charter School 268-0854
Chapter 5
Websites and Other Information

American Academy of Pediatricians Children's health topics-www.aap.org

Association for Persons with Severe Handicaps Advocacy and information for people with Handicaps (a.k.a. TASH) various handicaps-www.tash.org

Assn. of Regional Center Agencies Information on Calif.'s 21 Regional Centers-www.arcanet.org

Autism Society of America Autism advocacy and information-www.autism-society.org

Calif. Dept. of Develop. Services Regulatory agency for Regional Centers-www.dds.cahwnet.gov

Calif. Dept. of Health Care Services Calif. Dept. of Health Care Services and the Calif. Dept. of Public Health web site-www.dhs.ca.gov

Calif. Dept. of Health Care Services Medi-Cal services web site-www.medical.ca.gov

Calif. Dept. of Mental Health Mental Health services web site-www.dhm.cahwnet.gov

Calif. Dept. of Public Health, Health information-www.dhs.ca.gov

Calif. Disability Comm. Action Network Advocacy, information and news-www.cdcan.us

Calif. State Council on Developmental Disabilities Advocacy and information on developmental disabilities-www.senweb03.senate.ca.gov/autism/reportsinformation.html

Cambridge Center for Behavioral Studies Behavioral information, including autism-www.behavior.org/autism
Center for Disease Control Health and safety information-www.cdc.gov
County of Del Norte County of Del Norte-www.co.del-norte.ca.us
Health Department Del Norte County Health Department-
www.dnco.org/cf/pubweb1.cfm?topic=Health%20Department

County of Humboldt County of Humboldt-www.co.humboldt.ca.us
Health Department Humboldt County Health Department-
www.co.humboldt.ca.us/health
Health info for people with developmental disabilities-www.ddhealthinfo.org
Health info for people with developmental disabilities-www.ddmed.org
Developmental Behavioral Pediatrics Child development and behavior information-
www.dbpeds.org
Directory of Regional Centers From DDS website-
www.dds.cahwnet.gov/RC/RCList.cfm
Disabilities Dictionary Information on disabilities-
www.brookespublishing.com/dictionary
Emergency Preparedness Emergency Preparedness for people with DD-
www.dhh.louisiana.gov/offices/publications.asp?ID=77&Detail=1193
First Signs Early ID of children with developmental delays-www.firstsigns.org
Food Pyramid Nutrition and diet information-www.mypyramid.org
Humboldt Comm. Switchboard Comprehensive list of resources in Humboldt-
www.theswitchboard.org
Autism society-www.autismsocietyca.org
Defeat Autism Now-www.defeatautismnow.com
Autism Speaks-www.autismspeaks.org
Talk About Curing Autism (TACA)-www.child-autism-parent-cafe.com
CHAPTER FIVE
CONCLUSION

This project has detailed to parents the ways in which grief may enter in their lives after their children’s diagnosis of autism occurs. It offers options of ways to cope with the grief, options parents have for various services that are available to them, and information on behavioral techniques and their utilization. It provides information in regard to schools in the area and the contact information for those schools as well as links to a variety of web sites that offer information on autism, services, and general information on children.

After thorough review and analysis of my culminating experiences, I discovered that parents in the local area are not being informed of the services and information that should be available to them in a easy to use guide. The primary goal of providing information to parents is to give them the knowledge and power to put together a team of people that will be able to best help their child and family.

Limitations of the Research

One limitation of my research is the small return rate on the survey that was sent out to the families in our area. With a small sample of the total population of families affected by autism in our area, it is unclear whether the results are representative of the needs of the general population. There are a few possible reasons for the low sample size. Several of the surveys sent out were returned to me undeliverable so the addresses could have been wrong, or the families may have
moved. Another reason may be that the families were happy with what services they were receiving and did not feel they could contribute to the project.

Another limitation of my research is that this handbook focuses on a small rural community in which resources and services are limited and is not applicable to any other community.

There were limitations with in the school information chapter. Due to the restructuring of schools in the local community, I was unable to list teachers or specific classrooms at the schools. Thus, parents must to find out further information about the schools on their own.

The final limitation is that the web site information is limited to only the name of the site. Giving further information about each web site would help the families know which site would be the most helpful without having to surf the entire list to find specific information.

**Implications for Future Research**

Recommendations for future research are many. More information could be researched about what the schools have to offer in each community. This would allow parents to make the best decisions on where to send their children so as to best meet their specific needs. Sharing this project with the parents, professionals, and educators may help to bring to the forefront the limited resources that are available to families and the need for additional support in areas such as Del Norte County.

Another recommendation would be to analyze the effectiveness of the agencies in regards to the services they provide. This will give the families a comparative
analysis of what the agency says they can do versus what they are actually able to do.

Field testing copies of this handbook with parents and getting feedback on it would provide helpful knowledge of how it can be modified and what information is lacking in order for a final copy to be more comprehensive and useful.

The final step in completing this project is to get it printed in a format that can be made available to families, doctor offices, professionals, and regional centers throughout Humboldt and Del Norte Counties. The ultimate goal of this project is to inform and encourage parents to make the most informed decisions for their children with autism.
REFERENCES


