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An Occupational Therapy Based Education Course for Caregivers of Children with Pervasive Developmental Disorders

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An Occupational Therapy Based Education Class for Caregivers of Children with
Pervasive Developmental Disorders

by

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This Scholarly Project Paper, submitted by Krystal Cook in partial fulfillment of the requirement for the Degree of Master’s of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Faculty Advisor

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INTRODUCTION

Pervasive Developmental Disorders (PDDs) are a class of disorders involving a range of deficits. Children diagnosed the PDDs typically have disturbances in social interaction and communication as well as disturbances of behaviors, sensory processing, and perceptual processing (Case-Smith, 2005). Children with PDDs generally do not have problems in all areas of functioning; they often have one or two specific problem areas and function very well in other areas. The Pervasive Developmental Disorder Spectrum includes the following diagnoses: Autism, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Development Disorder Not Otherwise Specified (PDDNOS). An increasing number of children are being diagnosed with Pervasive Developmental Disorders. There are three possible reasons for the rise in number. First, the definition of Autism and its related disorders have been broadened. Asperger’s Disorder has just recently been diagnosed as its own unique disorder so there is not a way to measure the number of people affected by this disorder. Second, there has been a significant increase in the interest among all types of health professionals and parents. Third, there may be a true considerable increase in the cases of Autism and its related disorders. If it is true that there is a rise in the number of cases, the cause is yet unknown, therefore unable to be prevented (Wing, 2001). Pervasive Developmental Disorders are diagnosed in every racial, ethnic, intellectual, and socioeconomic background.
Occupational therapists address a variety of aspects with children diagnosed with Pervasive Developmental Disorders. In addition to direct intervention to the child, occupational therapists are being called upon to be educators to parents and caregivers of children with Pervasive Developmental Disorders to assist in expanding their knowledge to help and understand their children. One goal of therapy is parent education, which aims to strengthen families by providing appropriate, useful education and support. An assortment of learning opportunities and supportive activities are presented to enable parents to improve their understanding of their own children.

Parents and caregivers often have questions regarding the behaviors displayed by their children, appropriate home care, and professional treatments provided to their children. Although there is not a treatment that can cure any of the Pervasive Developmental Disorders, the earlier the treatment begins the better the prognosis. Parents are uncertain where to go or who to contact for answers. A wealth of medical information is available to parents however, there is a need for ‘parent friendly’, jargon-free information appropriate for the lay audience. There is a need for a more client-centered approach to give the parents the most beneficial and worthwhile information.

A comprehensive review of the literature was conducted on the topics of Pervasive Developmental Disorders, behavioral symptoms, professional care, and prognosis. In addition, information regarding past parental education classes/programs will be reviewed to determine what methods have been proven effective and what parents like, expect, and desire from an education course. From the information gathered, an
occupational therapy based education course will be designed specifically for parents and/or caregivers of children with Pervasive Developmental Disorders. The goal of this education course will be to help parents better understand and care for their children. This education course will give parent’s caregivers some of the factual information necessary to begin to understand their child.

The Canadian Model of Occupation Performance (CMOP) will serve as a guide to establish a client-centered parent education course. The client-centered approach will enable the occupational therapist and the parents to collaborate on and establish learning objectives unique to the participants of the education course.

**Terminology**

**activity of daily living (ADL):**

**aphasia:** total or partial loss of the power to use or understand language

**apraxia:** able to understand spoken language and sometimes written text, but unable to speak

**asperger’s syndrome:** a pervasive developmental disorder characterized by severe impairments in social skills and restrictive repetitive behaviors and interests, but without significant delays in language development

**ataxia:** an inability to coordinate muscle activity during voluntary movement

**auditory training/retraining:** a techniques used to desensitize a person to painful or distracting sounds
augmentative communication: any type of tool that enhances communication, for example: picture boards, keyboards, touch-talkers

autism: a mental disorder characterized by severely abnormal development of social interaction, verbal and nonverbal communication. The individuals may adhere to inflexible, nonfunctional routines/rituals. They often have a limited range of interests and appear unable to understand others’ feelings.

autism spectrum disorder (ASD):

behavior modification: a system of training by which reinforcers are used to change behavior

childhood disintegrative disorder (CDD):

cognition: ability to understand and know the environment

developmental disability: a disabling condition that affects intellectual, functional, and/or academic development of a person

DSM:

dual diagnosis:

dyspraxia: difficulty with smooth, coordinated voluntary movements involved with speech

echolalia: involuntary parrot-like repetition of a word or sentence just spoken by another person

expressive language: the ability to use language to express oneself

fine motor skills: the ability to use small muscles in the face, hands, fingers, and tongue to make small, accurate movements

genetics: the study of conditions resulting from inherited components of DNA

gross motor skills: the ability to use and control large muscles of the abdomen, arms, and legs
**hypersensitivity**: painful reaction to sensory input, abnormal sensitivity, an exaggerated response

**hyposensitivity**: little to no reaction to sensory input, subnormal sensitivity, response to stimuli is unusually delayed or lessened

**Individualized Education Program (IEP)**: an individualized special education program designed to meet the distinctive needs of each specific child with educational disabilities

**mental retardation**: sub-average general intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behavior

**MMR**: abbreviation for measles, mumps, and rubella vaccine

**mute**: unable or unwilling to speak

**neurologist**: physician specializing in medical problems associated with the brain and spinal cord

**occupational therapists**: therapists who specialize in improving fine motor and adaptive skills such as writing, grasping, pinching, buttoning, cutting

**oral motor**: relating to the muscles in and around the mouth

**perseveration**: pervasive developmental disorder (PDD): a group of mental disorders characterized by distortions in the acquisition of the multiple basic psychologic functions necessary for the elaboration of social skills, language skills, and imagination, also characterized by restricted or stereotypical activities and interests

**pervasive disorder not otherwise specified (PDDNOS)**: pervasive disorder not otherwise specified

**physical therapist**: therapists who address gross motor skills such as walking, running, jumping

**prognosis**: a forecast of the probably course and/or outcome of a disease

**proprioception**: a sense of the location of body position and movement, especially the limbs
psychomotor retardation:

receptive language: the ability to understand spoken and written communication as well as gestures

respite care: caregivers who offer the primary caregivers temporary relief from the demands of caring for a person with a disability

rett syndrome: a pervasive development disorder characterized by the developmental of several specific deficits after an apparently normal prenatal and perinatal period, including deceleration of head growth, loss of purposeful hand skills, stereotypical hand movements, impairments in expressive and receptive language, and significant psychomotor retardation

savant: a person who demonstrates an extraordinary ability in particular areas

self-abusive behaviors:

self-stimulating behaviors: self-initiated, repetitive movements presumably performed to relieve stress, examples include: rocking, spinning, flapping, and the unusual manipulation of inanimate objects

sensory integration: a therapy that regulates the effect and response to input from various sensory symptoms

speech and language pathologists: a therapist who works to improve speech, language skills, and oral-motor activities

stereotypy: constant repetition of certain meaningless gestures or movements

tactile: relating to touch or the sense of touch

tactile defensiveness:

vestibular: sensory system located in the inner ear that allows the body to maintain balance
CHAPTER II
PERVASIVE DEVELOPMENT DISORDERS

Pervasive Developmental Disorders (PDDs) are a group of disorders involving delays in the development of many basic skills. Generally, these children have trouble understanding their environment. Characteristics these classes of disorders have in common include: impairments in social interaction, impairments in verbal and nonverbal communication, imaginative play, repetitive actions, and they display a limited number of interests. Children with PDDs generally do not have problems in all areas of functioning; they often have one or two specific problem areas and function very well in other areas. The Pervasive Developmental Disorder spectrum contains numerous specific subtypes including: Autism, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Development Disorder Not Otherwise Specified (PDDNOS). These disorders will be further discussed in the next section (Thorwarth Bruey, 2004).

Autism

Autism is the most commonly diagnosed PDD (Thorwarth Bruey, 2004). The term “Autism” was first used in 1911 by a Swiss psychiatrist, Eugen Blueler. Blueler described the withdrawal from the outside world that he was seeing in some of his adult patients suffering from schizophrenia (Sadock & Sadock, 2002). Dr. Leo Kanner first described this disorder in the early 1940’s when he began to see distinctions between children diagnosed with schizophrenia and those diagnosed with Autism (Thorwarth
In 1980, the American Psychiatric Association’s Diagnostic Statistical Manual included a definition of Autism for the first time (American Psychiatric Association, 1980). Autism is sometimes referred to as early infantile Autism, childhood Autism, or Kanner’s Autism. Autism is four to five times more common in males than in females. However, females diagnosed with Autism have significantly lower IQs and are more severely impaired (APA, 2000). The reason for the significant difference between the diagnostic numbers between the sexes is unknown. It has been found throughout the world in families of all racial, ethnic, and social backgrounds. The reported prevalence of Autism ranges from 2 to 20 out of every 10,000 births (APA, 2000).

The exact causes of Autism and a majority of the other Pervasive Developmental Disorders are currently not known (WebMD Health, 2004; Thowarth Bruey, 2004). Research has shown parental personality or child-rearing practices do not cause Pervasive Developmental Disorders, as was believed to be the fact in the past (Satkiewicz-Garyhardt, Peerenboom, & Campbell, 1998). Most researchers believe that they are caused by genetic factors, infectious diseases, neurobiological abnormalities, allergies, prenatal, perinatal, or neonatal trauma, or neurochemical abnormalities. They believe the cause is likely due to a combination of one or more of the above in addition to familial genetic factors and neurobiologic vulnerability (Case-Smith, 2005).

The measles, mumps, rubella (MMR) vaccination has been a recent cause for concern. There has been an increase in the diagnoses of various PDDs, along with an increase in the distribution of the MMR vaccine. However, no proof has been found to
date indicating there is a correlation between the two (WebMD Health, 2004). The MMR vaccination is usually given around the time parents would begin to notice some of the symptoms in their children. Problems during birth tend to be more common in children with Pervasive Developmental Disorders as compared to the average birth. Previously, it was thought the difficult births resulted in the child having a PDD. It is now believed pre-existing abnormalities in the child may attribute to their difficult births. Further, it is believed the increase in the number of cases of Pervasive Developmental Disorders is due to wider diagnostic criteria (Thorwarth Bruey, 2004).

Asperger’s Disorder

Asperger’s Disorder is a relatively new diagnosis first included in the American Psychiatric Association’s diagnostic manual in 1994 (Thorwarth Bruey, 2004). Asperger’s Disorder is considered a sub-type of Autism that is differentiated by a later onset and unaffected speech. Asperger’s Disorder is similar to Autism in many ways. It is sometimes referred to as “high functioning Autism”. Children with Asperger’s Disorder tend to function better in daily life. They generally have an average to above average intelligence and language development. However, social skills do not come naturally to this group of individuals. Children with Asperger’s Disorder display a lack of empathy, inappropriate, one-sided interaction, repetitive speech, poor non-verbal communication, intense absorption in certain subjects, and ill-coordinated movements (WebMD Health, 2004). Motor development may be delayed and/or clumsiness may be noticed in children diagnosed with Asperger’s Disorder. Asperger’s Disorder is also characterized by strong interests in a limited number of areas. They may appear to be eccentric and carry on long conversations about their limited area of interest (Cohen,
Many people diagnosed with Asperger’s Disorder go on to have a successful career where there is little human contact and optimize the use of their special interests, such as computers (Waltz, 2002).

Asperger’s Disorder is five times more common in males than females (Case-Smith, 2005). The exact number of people affected by it is unknown. The reported prevalence of Asperger’s Disorder ranges from 3 to 36 out of every 1000 births (Thorwarth Bruey, 2004; WebMD Health, 2004). The cause of this disorder is not known.

Childhood Disintegrative Disorder

Childhood Disintegrative Disorder, also known as Heller’s syndrome, dementia infantilis, or disintegrative psychosis, is described as “a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development.” (APA, 2000). The areas of functioning that are affected include: language, social skills, motor skills, play, and bowel/bladder control. Aggressive behaviors may increase as well. Unfortunately, severe mental retardation usually accompanies this disorder. A majority of children with CDD are boys, however the male to female ratio is unknown (APA, 2000). Childhood Disintegrative Disorder is also a rare disorder. It is diagnosed in approximately 5:10,000 births (Thorwarth Bruey, 2004). The cause of this disorder is also not known.

Rett’s Disorder

Rett’s Disorder is a rare neurodegenerative disorder that is exclusive to females and is characterized by a progressive loss of intellectual function, loss of motor skills, and stereotypic hand movements. Rett’s Disorder was first identified in 1966 by Andreas
Rett, an Austrian physician (Thorwarth Bruey, 2004.) Children with Rett’s Disorder develop normally until approximately 18 months, when parents notice a change in their child’s behavior. Then, the children lose some of their previously acquired skills, specifically gross motor skills. Some girls with Rett’s Disorder do recover a few abilities previously lost, however this is rare (Waltz, 2002). Rett’s Disorder is usually associated with severe to profound mental retardation (APA, 2000). Children diagnosed with Rett’s Disorder display a slowing of the growth of the head, resulting in a plateau of the brain. This results in difficulties in gait and balance, called ataxia. One of the most common behaviors displayed by children with Rett’s Disorder is hand-wringing or hand-washing. Rett’s Disorder affects only the female gender; it occurs in 1:15,000 female births in the United States (Thorwarth Bruey, 2004). Rett’s Disorder is a genetic disorder caused by a defective MECP2 gene on the X chromosome caused by an inborn error in metabolism. Why this happens is unknown. Rett’s Disorder results from the mutation of the gene that makes methyl cytosine binding protein, resulting in large amounts of this protein (WebMD Health, 2004). Rett’s Disorder occurs in children from every racial, ethnic, intellectual, and socioeconomic background.

Pervasive Developmental Disorder Not Otherwise Specified

Pervasive Development Disorder Not Otherwise Specified (PDDNOS) is a diagnostic category for children who do not fully meet the criteria of any of the disorders listed above. These children are often social, but have significant problems with communication and play. None of the symptoms these children experience are as severe as the other disorders (APA, 2000). PDDNOS is sometimes referred to as an Autistic disorder. The cause of PDDNOS is not known.
There is a wide range of symptoms and severity of symptoms displayed by children with Pervasive Developmental Disorders. This is why the disorders are frequently called the Pervasive Developmental Disorder spectrum. Severity can range from mild to disabling. Individual abilities, intelligence, and behaviors also vary greatly between children.

Making a diagnosis of a Pervasive Developmental Disorder and then differentiating between which of them it is has become a difficult task. “There are no tests yet developed that can be used to make a definitive diagnosis of Autism nor any that can tell the difference between sub-groups with Autistic disorders.” (Wing, 2001 p.6). Diagnoses are typically made by reviewing past and current behaviors and ruling out other disorders.

TREATMENT

There isn’t a treatment that cures any of the Pervasive Developmental Disorders, but treatment does assist people with Autism develop to their full potential. Children with PDDs peak with therapy which is highly structured and specialized. There are educational and vocational programs for people with PDDs to help them with communication and decision-making skills. To improve overall function, the American Academy of Pediatrics recommends behavioral training and management, speech therapy, occupational therapy, physical therapy, medical management, community support, and parent training (WebMD Health, 2004).

PARENT’S RESPONSE TO A PDD DIAGNOSIS

Parents typically experience a wide variety of feelings and emotions when their child has been diagnosed with a Pervasive Developmental Disorder. Initially, parents
may feel relief. The diagnostic process is a long and difficult one and finally parents receive answers for their children’s behaviors. Shortly after, parents begin to feel relief that their child has received a diagnosis that explains their behavior, they may begin to go through a range of emotions that are commonly associated with the stages of grief, documented by Kübler-Ross (Kübler-Ross, 1969). The parents may feel shock, depression, denial, guilt, shame, isolation, panic, anger, bargaining, and finally acceptance (Satkiewicz-Gayhardt, et al., 2004). A parent doesn’t necessarily feel all of these emotions or in this particular order. Shock usually happens when the initial diagnosis is made. The parents of a formerly typically developing child have been given the news that their child is not “normal”. A number of the parents’ expectations and plans change when they discover their child has a PDD. Occasionally, parents go through a period of denial and believe their must be a mistake in with their child’s diagnosis. A period of guilt often follows with parents believing they were somehow responsible. When a Pervasive Developmental Disorder is diagnosed, parents may imagine the worst. They begin to panic and wonder who should they tell, how do they tell them, and are they going to be able this unexpected situation? Anger sets in with many questions of “why”. “Why my child?”, “Why me?”, “Why, when we so carefully planned our pregnancy and did all the healthy things should my baby be burdened with this disability?” are common questions parents ask during their period of anger. Bargaining is when parents try to make a deal to make the diagnosis of their child go away. Finally, parents approach their child’s diagnosis with hope and acceptance. They have begun to understand Pervasive Developmental Disorders and accept their child (Satkiewicz-Gayhardt, et al., 2004).
EDUCATING PARENTS

Limited research is available regarding education classes or programs for parents of children with Pervasive Developmental Disorders. Therefore, a search was conducted to locate research studies on parental education courses of different kinds to determine characteristics of the courses parents determined were worthwhile or beneficial and some of the recommendations for improvement.

Education classes/courses have been introduced to address a variety of topics to help parents better understand their children. Petersson, Petersson, and Hakansson (2004) sought to determine what makes parental education high-quality, beneficial, and worthwhile. The researchers conducted follow up interviews with sixty-one Swedish parents after they had attended a healthcare parental education program to learn more about their experiences and expectations. The parental education class was set up for first time parents and others to learn basic parenting skills. The education program consisted of 8 to 10 meetings that lasted approximately two hours. The group consisted of six to eight parents in each meeting. A majority of the group members were first-time, married parents. The leader of the meetings was a nurse. The parents stated they found parental education valuable during a child’s first year of life. Social contact established between parents who attended the program was considered to be an important asset. The gathering of the parents allowed them to share common experiences and advice to assist in caring for their children. “It was so instructive to hear how the others coped in their role as parents. It’s no good just listening to the experts. You need to know how others solve their problems, tricks of the trade, that’s what is useful.” (Petersson, Petersson, & Hankansson, 2004, p. 85). The classes gave the parents time with adults and support they
had not been previously receiving. “Parent groups are very good for those who don’t have family or parents nearby as you have no one to ask when a problem arises.” (Petersson et al., 2004, p. 85). The parents appreciated the fact the nurse was knowledgeable and created a relaxing environment where the parents felt at ease to express their concerns. The parents expressed desire for more information on problems in marital relationships, familial stress, and the interaction between child and parents. Overall, the results of this study indicate the parents found the education classes as an opportunity to exchange experiences, seek out social support, and provided a break from their daily routines. The parents desired the classes to be structured and organized. The parents felt the education classes need to be appropriate for the target audience and strive to provide information to socially vulnerable groups who may need the information, but not know where to locate resources. Some of the parents involved in this study continued to meet after the classes had ended, proving they had established a social support system in fellow class members (Petersson, et al., 2004).

Miller and Sambell (2003) sought to determine what parents felt they needed from a parent support education class. The purpose of this study was to understand and interpret the ways parents saw various parenting support, what their intentions were, and how this reflected their individual beliefs, attitudes, and assumptions. The researchers used focus groups encouraging parents to share their perceptions of their needs and how they felt these needs were being addressed. All of the parents in the study were mothers, however they came from both rural and urban locations and ranged in age from late teens through mid-fifties. Teaching conducted by an expert who can present significant facts and knowledge was viewed by some as the most advantageous. Others believed that to
effectively learn they must make sense of the information and the information must be presented in a personally meaningful way. The child’s needs are crucial information to be included to determine the ways adult-child interactions are developed and understood. Three models of learning emerged from parents views of learning including: dispensing model, relating model, and the reflecting model. The dispensing model focuses on the content and knowledge of learning. The information in this model was provided by a professional. The relating model focuses on the development of the parent. Value was placed on learning from other parents’ experiences. The reflecting model held parent-child relationships important. The parents involve themselves in self-reflection instead of asking others for advice. Value is placed on developing understanding. All of the participants came to the support groups for information provided by the dispensing model. The reflecting model assisted in developing a comfortable learning environment for a majority of the participants as well. This study showed parents attended the education classes mostly for the factual information, but enjoyed and valued being in the comfort of other parents, in addition to learning from them and their experiences (Miller & Sambell, 2002).

Zeedyk, Werritty, and Riach (1997) sought to determine what makes an effective parent education program. A group of mothers were gathered to determine the real needs and interests of parents. The mothers reviewed information from various existing parenting programs to determine what were beneficial topics, materials, and publicity strategies. From the information gathered from the mothers, the Parents All Together Lending Support (PALS) Parenting Support Program was developed. The format of PALS consisted of 1 ½ hour courses that focused on a particular topic. The courses
spanned through a six-week period. Group discussion, worksheets, videos, and homework were the teaching methods used. Group discussion allowed parents time to exchange their experiences, advice, etc. The PALS program identified four principles including: building on existing strengths, identifying the behavior you wish to change, considering the range of tools that could assist in accomplishing change, and developing an action plan for making the change. A total of 75 parents, ranging from 16 to 45 years of age, participated in the 17 groups. The children of the participants ranged in age from 8 to 23 years. The group sizes ranged from two to seven participants. Small group sizes allowed for bonds and relationships to be easily established. The PALS program was found to be effective in changing parents’ behaviors towards their children. A benefit of the program was the opportunity to meet other parents to share experiences, challenges, advice, etc. The lack of social supports is one of the major reasons professionals refer parents to parenting programs. The most beneficial fact determined by establishing the PALS program was the need for group members “to feel ownership of the program” (Zeedyk, Werritty, & Riach, 2002, p. 331). This was accomplished by including the parents in the decision making of which materials would be covered, letting attendance be voluntary, letting the parents be involved in the development of the program, and letting them determine how to carry out publicity of the program. “The importance of parent involvement has been stressed by Wolfendale (1999), who argues there is no further need for research that tells us what parents need unless they are regarded as part of the solution rather than as part of the problem.” (Zeedyk et al., 2002, p. 331).

Shepard and Carlson (2003) summarized school-based prevention programs with parental involvement to provide an overview of the existing research for education
professionals. Twenty school-based prevention programs with parental involvement were reviewed. They describe increased implementation of prevention programs in schools in addition to increased funding. Some of the components of a well designed parental prevention education program include: having a duration time adequate enough to provide education, considering the parents a part of the solution, having a flexible program, and having parents and school members evaluate the program. Each of the programs reviewed had clearly defined goals. Some of the unique components programs included: family fun nights, home curricula, and parent skills training. The school was identified as an ideal setting for parental prevention programs.

Wood III and Baker (1999) too, identified an increase in the number of schools involving the parents through parental education classes and researched parents’ preferences, behaviors, and beliefs towards parental education classes. The purpose of their research was to assist schools in developing informative education classes which address the needs of the parents. The 395 participants in this study were from two elementary schools in southeastern United States. The sample obtained was culturally diverse and low-income parents. Questionnaires were sent home with the children from the two elementary schools. The questionnaire measured parents’ interest in various aspects of parental education classes including parents’ interest in various formats and topics, barriers to participation, and current parenting practices. The results indicated parents prefer short sessions on a single specific topic. The parents preferred the classes to be held in the evening hours in a group setting. The cost of the education programs, time of day sessions are offered, work, babysitting, transportation, and privacy were stated as significant barriers to participating in various parental education classes. It was
determined that low socioeconomic status parents are less likely to attend school based parental education classes. It may be beneficial for schools to provide babysitting and transportation to assist low-income parents. Videotapes or printed materials should be readily available for parents who are unable to attend, but have the desire to learn. Overall, this study concluded most parents are interested in school-based parental education classes, however may not be able to participate for various reasons explained above. An extended effort may need to be made to include low-income, culturally diverse parents (Wood III & Baker, 1999).

OCCUPATIONAL THERAPISTS AS EDUCATORS OF ADULTS

Occupational therapists address a variety of aspects with children diagnosed with Pervasive Developmental Disorders. In addition to direct intervention to the child, occupational therapists are increasingly being called upon to be educators to parents and caregivers of children with pervasive developmental disorders. Occupational therapists can assist in expanding their knowledge to help and understand their children.

Discussing treatment options with the parent or caregiver of a child receiving treatment is essential because, next to the child, they are the most important member of the treatment team (Stancliff, 1996). The occupational therapist can assist in developing solutions to transfer the skills learned in therapy into the home environment. The parent and the therapist can collaborate on what goals are important and on strategies to help the child achieve his or her maximum potential. Education is listed as a type of intervention in the Occupational Therapy Practice Framework. The education process is defined as “An intervention process that involves the imparting of knowledge and information about occupation and activity and that does not result in the actual performance of the
“occupation/activity” (American Occupational Therapy Association, 2002). Education classes provide parents with support and needed knowledge to effectively care for their child. There is evidenced that indicates the more a parent knows about child development, the better prepared they are to promote the best possible development (Case-Smith, 2005).

Occupational therapists are knowledgeable in the area of treatment for children with Pervasive Developmental Disorders, however it is important for the therapist must be able to admit they don’t have all of the answers. Families admire health care providers who keep up to date with technology, are willing to admit when they do no know all the answers, but are willing to find out (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

When teaching an education class, the first session is extremely important. Motivation is either established or dissolved and first impressions are made both about the instructor of the class and the class materials. It is a good idea, as the class instructor, to get to know your audience as well as you can before the initial session, whether it be calling them on the telephone or sending them a survey. Information the instructor may want to gain includes: why they are attending the event, what they want to get out of it, what they already know about the subject, and what would be useful for them to know. By doing this the instructor can gain vital information about what the class participants want and expect. The learners may want advance information, as well. It may be beneficial to send the class participants a welcome letter, course outline, a map with instructions to the class location, additional costs, details of equipment/supplies they need to bring, and a reading list (Rogers, 2001).
During the initial session, the instructor should arrive early to greet participants and begin introductions. When the instructor introduces himself or herself, it is important the introduction include your name, passion for the subject, goals for the class, and what credentials. Ice-breakers are both fun and important. They give participants a change to meet other class participants and begin to relax. When the instructor gives the prepared lecture, focusing on human interest maintains people’s attention. Some ways of doing this include: making it personal, telling personal stories, and telling other people’s stories. It is important to keep in mind incentives for adult learning when preparing the lecture. Some of the incentives are wanting to be good parents and satisfying their curiosity. Also, they want to gain self-confidence, health, and increased enjoyment. In addition, adult learners want to save time, money, worry, doubts, risks, and discomfort (Knowles, 1980). It is essential the instructor convey confidence through his or her body language, mannerisms, and voice.

Rogers (2001) shares suggestions regarding ways to adapt teaching to the needs of adult learners. These include suggestions regarding general presentation, handout, environment, and accessibility. Rogers suggests when teaching adults, the most effective learning takes place when:

- They really want and need the knowledge
- They know how we will apply the information
- They will be rewarded on way or another for having it
- They can draw on their own experiences
- They can learn at their own pace and style
- They are stretched and challenged
They are supported

They are treated as individuals with unique needs by whoever is helping them learn (Rogers, 2001)

To assist in effective learning, handouts are a way for participants to take the information home with them to refer to as needed. There are a few common-sense rules that make handouts as useful as possible. First, attempting to write down every word the instructor intends to say will make the information overwhelming. Restrict the handouts to the main points and determine if someone who had not attended the class would be able to follow the handouts and gain valuable information. Using a font less than 12 point, having more than three colors, and using all capitalized headings will appear cluttered and hard to read (Rogers, 2001).

Questions by the participants often follow the lecture. It is important to maintain eye contact throughout the question and answer session and to listen carefully. Concluding with, “Did I answer your question?” is an effective way to determine if you have given the information the class participant was looking for. Upon completion of the session, it is beneficial to ask participants for feedback in order to improve the next session (Rogers, 2001).

The environment is also an important factor to consider when educating adults. The environment should be set up to facilitate maximum group contact and participation. In order to achieve that keep the space between chairs to a minimum, remove redundant chairs, let everyone be able to see everyone else without having to twist or turn, provide comfortable chairs, use a room that is not too big or too small, and utilize tables or desks that fit the purpose (Rogers, 2001).
When educating adults, the instructor must decide on a number of factors to ensure the class is accessible. The time the class is held should be at the time that is most convenient to the participants. Evening hours have proven to be the most convenient. In general, classes last between one to three hours, with the average length being an hour and a half. The general experience is that the days at the beginning of the week seem to work best, with the classes meeting one time per week (Knowles, 1980).

**OCCUPATIONAL THERAPY MODEL/APPROACH**

The Canadian Model of Occupational Performance (CMOP) provides direction for addressing occupational needs through client-centered therapy. It views the relationship between persons, environment, and occupation that results in a person’s occupational performance. Client-centered occupational therapy is defined as “an approach to service which embraces a philosophy of respect for, and partnership with, people receiving services” (Law, Baptiste, & Mills, 1995, p.253). The client-centered therapy enables the client to collaborate with the occupational therapist in order to establish meaningful goals. This approach allows the client to be an active participant in their care, has family involvement, provides information that is accessible, respects families and diversity and the choices they make, emphasizes open communication, encourages use of community supports, encourages parent to parent support, and facilitates client participation in all aspects of occupational therapy service (Law & Mills, 1998).

This approach has been chosen because the development of the product will involve the clients (parents) in the decision making of the content in the parental education course. Client-centered therapy enables the occupational therapist to recognize
clients’ experiences to further gain knowledge and provide the appropriate services. The client-centered approach represents the purpose and structure of the parental education course including: client autonomy and choice, being accessible and flexible, having the patients participate in decision making, involving the family, encourage parent decision making, respecting diversity, encouraging the use of community supports, providing an individualized services, parent-professional collaboration, encouraging parent to parent support, listening to the client, and providing information (Law & Mills, 1998).

Research has been reviewed to determine different aspects the parents felt made the parental education classes worthwhile and beneficial. Recommendations for change have also been presented. This knowledge will be used to develop a client-centered, occupational therapy based education course for parents of children with Pervasive Developmental Disorders.

CONCLUSION

The number of children being diagnosed with Pervasive Developmental Disorders is continuing to increase. Parents and caregivers frequently have many questions regarding the behaviors displayed by their children, appropriate home care, and professional treatments provided to their children. Medical information is widely available to parents however, there is a need for ‘parent friendly’, jargon-free information appropriate for the lay audience. There is a need for a more client-centered approach to give the parents information that is most beneficial to them.

Occupational therapists are being called upon to be educators to parents and caregivers of children with Pervasive Developmental Disorders. In addition to direct
intervention, occupational therapists are assisting in expanding parents’ knowledge to help them better understand and care for their children.

The Canadian Model of Occupation Performance (CMOP) will serve as a guide to establish a client-centered education course. The research reviewed has provided beneficial information regarding parents’ perspectives on various aspects of parental education courses. Determining what the parents want out of an education course will enable the occupational therapist to use a client-centered approach and collaborate with the parents to establish objectives the parents desire out of an education course.

In the next section, the methodology for the development of a client-centered parental education course for parents of children with PDDs will be discussed. In addition, an overview of the product and the relationship to the literature reviewed will be identified.
CHAPTER III
METHODOLOGY

A literature review and comprehensive research of various sources was completed on the topics of Pervasive Developmental Disorders, parent education, adult education, and the occupational therapist’s role as educator of adults. Research regarding parental education classes/programs was reviewed to determine methods which have been proven effective and parents’ expectations from education classes. This research was conducted prior to program development using OT search and Pub Med as search engines. WebMD Health.com was used to gather factual information regarding Pervasive Developmental Disorders. Internet searches were conducted on the topics of parental education classes, course descriptions, and course evaluations to determine how to effectively set up the course. In addition, research was conducted on theories and models of OT practice to determine which would be the most favorable choice to serve as a guideline for product development.

It was determined parents and caregivers often have variety of questions regarding their children, there is a wealth of medical information is available to parents. However, there is a need for ‘parent friendly’ information appropriate for the lay audience and for a more client-centered approach to give the parents the most beneficial and worthwhile information. A client-centered, occupational therapy-based education course was designed specifically for parents and/or caregivers of children with Pervasive...
Developmental Disorders to provide factual information necessary to understanding their children.

Chapter four will address the various components of the OT-based class for parents/caregivers of children diagnosed as having PDDs. The course contains the following: objectives for the course, informational paper on PDDs for the course instructor, introduction letter, environmental considerations, course location guidelines, power point presentation with written informational handouts available for course participants, resource list, terminology list, and a course evaluation form.
An Overview of Pervasive Developmental Disorders for the Course Instructor

Kids Count
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Introduction

The following information regarding Pervasive Developmental Disorders (PDDs) was organized to provide the occupational therapist with background information and general knowledge. The occupational therapist can use this fundamental knowledge to increase familiarity of Pervasive Developmental Disorders enabling them to provide parents with effective information regarding their children.

Pervasive Developmental Disorders are a group of disorders involving delays in development of many basic skills. Generally, these children have trouble understanding their environment. Children with PDDs do not follow the typical pattern of child development (National Institute of Mental Health, n.d.). Characteristics these classes of disorders have in common include: impairments in social interaction, impairments in verbal and nonverbal communication, imaginative play, repetitive actions, and they display a limited number of interests. Children with PDDs generally do not have problems in all areas of functioning; they often have one or two specific problem areas and function very well in other areas. The Pervasive Developmental Disorder spectrum contains a number of specific subtypes including: Autism, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Development Disorder Not Otherwise Specified (PDDNOS) (Thorwarth Bruey, 2004).

Pervasive Developmental Disorders
There is a wide range of symptoms and severity of symptoms displayed by children with Pervasive Developmental Disorders. This is why the disorders are frequently called the Pervasive Developmental Disorder Spectrum. Severity can range from mild to disabling. Individual abilities, intelligence, and behaviors also vary greatly between children (WebMD Health, 2004).

Children diagnosed with Pervasive Developmental Disorders display abnormal responses to sensory stimuli. These children have difficulty filtering out unimportant stimuli. They may overreact, or under react to stimuli. In addition, some stimuli may be aversive to the child including various sounds, textures, tastes, and smells. Some stimuli that are considered background noise for “normal” people become something children with Autism become captivated with. The same child may have no reaction to other sounds in which the average person would attend to, such as their name being called. It is unknown why the tendency of children with Pervasive Developmental Disorders is to over attend to some stimuli and under attend to others. Another abnormal response to stimuli has to do with foods eaten. They may avoid certain food textures, odors, or colors. Children with Pervasive Developmental Disorders may insist the food they eat be the same texture or color, or they will refuse to eat it (NIMH, n.d.).

Development in the area of motor skills may be relatively normal. Communication, social, and cognitive skills have shown to be significantly delayed. Some skills may appear, and then disappear.

Some, 10%, of children diagnosed with Pervasive Developmental Disorders have exceptional skills in mathematics, music, memory, drawing, etc. “Autistic savants” is a term used to describe the children with exceptional skills in specific areas. However,
unfortunately nearly 75% of children diagnosed with Autism have some degree of mental retardation (WebMD Health, 2004).

Overall, general symptoms of Pervasive Developmental Disorders include:

- Difficulty with verbal communication, including problems using and understanding language
- Difficulty with non-verbal communication, such as gestures and facial expressions
- Difficulty with social interaction, including relating to people and to his or her surroundings
- Unusual ways of playing with toys and other objects
- Difficulty adjusting to changes in routine or familiar surroundings
- Repetitive body movements or patterns of behavior, such as hand flapping, spinning, and head banging
- Changing response to sound
- Temper tantrums
- Difficulty sleeping
- Aggressive behavior
- Fearfulness or anxiety (WebMD Health, 2004).

**Autism**

Autism is the most commonly diagnosed PDD (Thorwarth Bruey, 2004). The word Autism has its roots in the Greek language. It comes form the Greek word autos, meaning self. As early as the eighteenth century, many medical texts began describing
children now believed to have had Autism, or another similar PDD. The children were described as mute, aloof, and possessing unusual memory skills. The term “Autism” was first used in 1911 by a Swiss psychiatrist, Eugen Bleuler. Bleuler described the withdrawal from the outside world that he was seeing in some of his adult patients suffering from Schizophrenia (Sadock & Sadock, 2002). Dr. Leo Kanner first described this disorder in 1943. At that time, Dr. Kanner was a child psychiatrist at the Johns Hopkins University. He saw distinctions between the children he diagnosed with Autism and those diagnosed with childhood schizophrenia. Dr. Kanner noted the eleven children he had been studying for several years shared several characteristics, for example isolation. He thought Autism was caused by psychogenic factors related to cold and unloving parents. Dr. Kanner believed people diagnosed with Autism had the inability to form relationships (Thorwarth Bruey, 2004).

In the 1960’s, advances in the treatment and diagnosis of Autism were made. In 1977 the first definition of Autism was published by the Autism Society of America (Autism Society of America, 1997). In 1980, the Diagnostic Statistical Manual included a definition of Autism for the first time (American Psychiatric Association, 1980).

Autism is a disorder of the brain that interferes with normal development in the areas of the brain responsible for social interaction and communication skills. Children with Autism appear to be developing normally until 12 to 24 months when symptoms of Autism start to develop (Thorwarth Bruey, 2004). This change in behavior is sometimes followed by a fever. This fever may be caused by some form of trauma or encephalitis. The fever and the beginning of Autistic-like symptoms may follow a stressful event such as moving or the birth of a new sibling. The psychological causes are believed to bring
out the Autism at that time, when the child was vulnerable to develop Autistic behaviors. Parents become concerned when their child doesn’t babble, don’t like to be held, and appear to be deaf. There are no congenital signs of Pervasive Developmental Disorders and symptoms of the disorder are difficult to diagnose in infancy (Wing, 2001).

Autism is referred to as early infantile Autism, childhood Autism, or Kanner’s Autism. Autism is four to five times more common in males than in females. However, females diagnosed with Autism have significantly lower IQs and are more severely impaired (APA, 2000). The reason for the significant difference between the diagnostic numbers between the sexes is unknown. Autism is a lifelong developmental disability. It has been found throughout the world in families of all racial, ethnic, and social backgrounds. The reported prevalence of Autism ranges from 2 to 20 out of every 10,000 births (APA, 2000).

Five general characteristics of children diagnosed with Autism include: failure to develop normal socialization, disturbances in speech, language, and communication, abnormal relationships to objects and events, abnormal responses to sensory stimulation, developmental delays and differences, which begin during infancy and early childhood (NIMH, n.d.).

Failure to develop normal socialization appears to be the most noticeable characteristic of Autism. Children don’t interact with others normally, appropriately, or even at all. Children with Autism often prefer to play alone. Autistic children display difficulty with nonverbal communication. Children with Autism avoid eye contact and don’t display normal facial expressions or understand those of others. They have extreme difficulty expressing emotion and difficulty understanding others’ emotions. They may
show little or no desire for physical contact such as hugging or cuddling. Children with Autism are described as living in a world of their own. In infancy, a child diagnosed with Autism may not participate in peek-a-boo, fail to imitate sounds, be overly quiet, and/or not cry appropriately (NIMH, n.d.).

Disturbances in speech, language, and communication are also very common in children diagnosed with Autism. Approximately 40% of those children are mute (Powers, 2000). Some children display repetition of words, called echolalia. A child may repeat single words, TV commercials, lyrics from songs, or any other spoken word. They may have little or no understanding of what they are saying. The child’s voice may sound flat or monotonous. They may also not be able to control the pitch or volume of their speech. Children diagnosed with Autism have difficulty learning to talk, starting conversation, and continuing conversation once they have begun (Powers, 2000).

Many children with Autism interact with objects in an abnormal, nonfunctional way. They may spin objects repetitively or flap them in their hands. They may play with toys in an unusual way, lacking the ability to begin imaginative play. Stereotypies are repetitive patterns of movement such as hand-flapping, hand-regarding, eye-gazing, body-rocking, grimacing, tapping, and vocalizations children with Autism sometimes participate in.

**Asperger’s Disorder**

Asperger’s Disorder is a relatively new diagnosis first included in the American Psychiatric Association’s diagnostic manual in 1994 (Thorwarth Bruey, 2004). Asperger’s Disorder is considered a sub-type of Autism that is differentiated by a later onset and unaffected speech. Asperger’s Disorder is similar to Autism in many ways. It
is sometimes referred to as “high functioning Autism”. Children with Asperger’s Disorder tend to function better in daily life and generally have an average to above average intelligence and language development. However, social skills do not come naturally to this group of individuals. Children with Asperger’s Disorder display a lack of empathy, inappropriate, one-sided interaction, repetitive speech, poor non-verbal communication, intense absorption in certain subjects, and ill-coordinated movements (WebMD Health, 2004). Motor development may be delayed and/or clumsiness may be noticed in children diagnosed with Asperger’s Disorder. Evidence of this includes an awkward gait and difficulty learning to ride a bike or catch a ball. Although children with Asperger’s function well in school, they appear to lack common sense. Asperger’s Disorder is also characterized by strong interests in a limited number of areas. They may appear to be eccentric and carry on long conversations about their limited area of interest (Cohen, 1998). Many people diagnosed with Asperger’s Disorder go on to have a successful career where there is little human contact and are able to optimize the use of their special interests, such as computers (Waltz, 2002). Children with Asperger’s Disorder have an average or above average intelligence (WebMD Health, 2004).

Asperger’s Disorder is five times more common in males than females (Case-Smith, 2005). The exact number of people affected by it is unknown. The reported prevalence of Asperger’s Disorder ranges from 3 to 36 out of every 1000 births (Thorwarth Bruey, 2004; WebMD Health, 2004).

There are many possible symptoms that can be displayed by children with Asperger’s Disorder. The symptoms can range from mild to severe. Because of this wide variety, two children with Asperger’s Disorder are not alike. Symptoms of
Asperger’s Disorder typically begin to be noticed around the time a child is preschool age. Some symptoms include: lack of social skills, dislike changes in routines, appear to lack empathy, speech may be flat and difficult to understand, may have a formal style of speech that is advanced for their age, avoid eye contact, unusual facial expressions or postures, preoccupation with one or a few interests, talk a lot about one favorite subject, delayed motor movement, heightened sensitivity, and may have advanced rote memorization and/or math skills (WebMD Health, 2004).

**Rett’s Disorder**

Rett’s Disorder is a rare neurodegenerative disorder that is exclusive to females and is characterized by a progressive loss of intellectual function, loss of motor skills, and stereotypic hand movements. Rett’s Disorder was first identified in 1966 by Andreas Rett, an Austrian physician (Thorwarth Bruey, 2004). Children develop normally until approximately 18 months, when parents notice a change in their child’s behavior. Then, the children lose some of their previously acquired skills, specifically gross motor skills. Mental and social development regress and the child shies away from social conduct and no longer responds to her parents (NIMH, n.d.). Some girls with Rett’s Disorder do recover a few abilities previously lost, however this is rare (Waltz, 2002). Rett’s Disorder is usually associated with severe to profound mental retardation (APA, 2000). Children diagnosed with Rett’s Disorder display a slowing of the growth of the head, resulting in a plateau of the brain. This results in difficulties in gait and balance, called ataxia (WebMD Health, 2004).

Rett’s Disorder is a genetic disorder. Rett’s Disorder is caused by a defective MECP2 gene on the X chromosome caused by an inborn error in metabolism. Why this
happens is unknown. Rett’s Disorder results from the mutation of the gene that makes methyl cytosine binding protein, resulting in large amounts of this protein (WebMD Health, 2004). Rett’s Disorder occurs in children from every racial, ethnic, intellectual, and socioeconomic background. It occurs in 1:15,000 female births in the United States (Thorwarth Bruey, 2004).

Children affected with Rett’s Disorder typically develop Autistic-like behaviors in addition to breathing irregularities, feeding and swallowing difficulties, growth retardation, impaired control of voluntary movements, and episodes of uncontrolled electrical activity of the brain resulting in seizures. One of the most common and easily identifiable behaviors displayed by children with Rett’s Disorder is hand-wringing or hand-washing movements (WebMD Health, 2004).

**Childhood Disintegrative Disorder**

Childhood Disintegrative Disorder, also known as Heller’s syndrome, dementia infantilis, or disintegrative psychosis, is described as “a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development.” (APA, 2000). The longer period of normal development before regression assists in differentiating this disorder from Rett’s Disorder (NIMH, n.d.). The areas of functioning that are affected include: language, social skills, motor skills, play, and bowel/bladder control. Unfortunately, severe mental retardation usually accompanies this disorder. Children diagnosed with Childhood Disintegrative Disorder develop normally for the first two years before regression begins. Social skills, bowel and bladder control, motor skills, communication, play skills, interpersonal interactions, and nonverbal behaviors are affected. Aggressive behaviors may increase as well. A
majority of children with CDD are boys, however the male to female ratio is unknown (APA, 2000). Very few children meet the criteria for Childhood Disintegrative Disorder. It is a rare disorder and is diagnosed in approximately 5:10,000 births (Thorwarth Bruey, 2004).

**Pervasive Developmental Disorder Not Otherwise Specified**

Pervasive Development Disorder Not Otherwise Specified (PDDNOS) is a diagnostic category for children who do not fully meet the criteria of any of the disorders listed above. These children are social, but have significant problems with communication and play. None of the symptoms these children experience are as severe as the other disorders (APA, 2000). PDDNOS is sometimes referred to as an Autistic disorder.

**Etiology**

The exact causes of any of the Pervasive Developmental Disorders are currently not known (WebMD Health, 2004; Thowarth Bruey, 2004). Research has shown parental personality or child-rearing practices do not cause Pervasive Developmental Disorders, as was believed to be the fact in the past (Satkiewicz-Garyhardt, Peerenboom, & Campbell, 1998). Most researchers believe that they are caused by genetic factors, infectious diseases, neurobiological abnormalities, allergies, prenatal, perinatal, or neonatal trauma, or neurochemcial abnormalities. They believe the cause is likely due to a combination of one or more of the above in addition to familial genetic factors and neurobiologic vulnerability (Case-Smith, 2005).

Genetic research has shown the cause of Pervasive Developmental Disorder, with the exception of Rett’s Disorder, is not linked to a single dominant or recessive gene.
Some of the infectious diseases thought to be part of the causes of PDDs are PKU, encephalitis, meningitis, rubella, and CMV. Viral infections of the mother or infant are thought to be an intermittent cause (WebMD Health, 2004).

Problems during birth tend to be more common in children with Pervasive Developmental Disorders as compared to the average birth. Previously, it was thought the difficult births resulted in the child having a PDD. It is now believed pre-existing abnormalities in the child attribute to their difficult births. Further, it is believed the increase in the number of cases of Pervasive Developmental Disorders is due to wider diagnostic criteria (Thorwarth Bruey, 2004).

Allergies are thought to be a cause of some Pervasive Developmental Disorders, making it an autoimmune disorder. The allergies could be to fungal infections, virus infections, vaccinations, or various foods (Wing, 2001).

The mercury-based preservative used in the measles, mumps, rubella (MMR) vaccination has been a recent cause for concern (NIMH, n.d.). There has been an increase in the diagnoses of various PDDs, along with an increase in the distribution of the MMR vaccine. However, no proof has been found to date indicating there is a correlation between the two (WebMD Health, 2004). The MMR vaccination is usually given around the time parents would begin to notice some of the symptoms in their children. Mercury-based vaccinations are no longer utilized in the United States (NIMH, n.d.).

Research is being conducted on an effect of being exposed to mercury, lead, or other heavy metals may contribute to the development of a PDD. Some evidence points
to genetic factors playing a role in the causes of PDDs. Therefore, further research is being conducted in this area as well (NIMH, n.d.).

**Diagnosis**

There is an importance in diagnosing a child with a PDD. Some parents and professionals believe labeling a child with a diagnosis categorizes them into a designated group where they will be treated the same as other children in their diagnostic category. However, a child receiving a diagnosis has a number of benefits. A diagnosis gives the parents a better understanding of their child’s symptoms and needs. A diagnosis guides appropriate treatment in the right direction. The parents will be able to find other parents/professionals with information on their child’s diagnosis and be able to establish a social support system. The child having a specific diagnosis aids in their ability to receive funding and treatment resources available to children with their specific diagnosis (Thorwarth Bruey, 2004).

Diagnosing a Pervasive Developmental Disorder and then differentiating between is a difficult task. “There are no tests yet developed that can be used to make a definitive diagnosis of Autism nor any that can tell the difference between sub-groups with Autistic disorders.” (Wing, 2000, p.6). Diagnoses are normally made by reviewing past and current behaviors and ruling out other disorders.

The diagnosis of a Pervasive Developmental Disorder is made primarily based on the existence of Autistic-like symptoms and is typically made before the child’s third birthday (Hansen & Atchison, 2000). Developmental screenings are typically completed during routine check-ups, or if a parent becomes concerned. There are an assortment of
screening instruments used to differentiate children with PDDs from other groups of disorders. Screenings do not provide a diagnosis, however they do provide an assessment to determine if a referral is necessary. If the screening is indicative of a PDD, further evaluation is completed (NIMH, n.d.). A diagnosis can’t be made unless the developmental history of the child has been examined. If a health professional discovers any prominent developmental delays, they should be further evaluated. The developmental delays include: no babbling, point, or other gestures by 12 months, no single words by 16 months, no two word spontaneous phrases by 24 months, with the exception of repeated phrases, and any loss of language or social skills at any age (WebMD Health, 2004).

A number of studies are being completed on determining if there are anatomical differences among people with Pervasive Developmental Disorder. There have been a number of areas of the brain in people with Autism that show anatomical abnormalities. The following abnormalities have been found in some, but not all autopsies of those with Autism and similar Pervasive Developmental Disorders. The parietal, occipital, and temporal lobes are larger in volume. There is a reduction in the size of the cerebellar vermis and gray matter in the cerebellum. There are a reduced number of Purkinje neurons in the vermis as well. There is an increase in the size and density of neurons in the limbic system. The amygdala and the corpus callosum are reduced in size. Studies have found increased levels of Serotonin in people diagnosed with Autism. There is also an increase in thickness in the frontal cortical regions. Serotonin is a neurotransmitter that controls sleep, mood, some types of sensory perception, body temperature regulation, and appetite (Waltz, 2002).
Prognosis

Certain aspects are indicators of a more favorable future for children with a Pervasive Developmental Disorder. Those indicators include an initial IQ over 60, some spontaneous speech by the age of six, less severe symptoms, and a more passive behavioral manner. With increasing cases of PDDs being diagnosed, more research is being done to improve the services and level of care available. Children on the severe end of the Pervasive Developmental Disorder spectrum tend to live a less independent future. Two-thirds of children with PDDs will not be able to lead independent adult lives. Other unfavorable factors include: development of a seizure disorder, inability to play appropriately with toys, and living in an unstable home environment (Hudson & Dixon, 2003).

Adolescence and Adulthood

Adolescence is a time of emotional turmoil for most children. It is accompanied by stress, confusion, and maturing sexuality. Some of the behaviors exhibited by children with PDDs may improve during this time. However, some behaviors may become worse as they are expressing some of their tension and confusion through Autistic or aggressive behaviors. Adolescence is also a time when children become more aware they are different from their peers (NIMH, n.d.).

Public schools are required to provide services until twenty-two years of age. Then, the family is faced with a number of challenges including: finding living arrangements, employment, programs, and facilities that will support the further
development of their young adult. It is important for parents to think about and discuss these issues before the time arrives (NIMH, n.d.). There are a number of possible living arrangements for a person diagnosed with a PDD. Some adults with Pervasive Developmental Disorders are able to successfully live independently with assistance with major issues such as finances. There are also government funds available for families to assist them in caring for their child at home. Information about these funds is available from the Social Security Administration. Foster homes and skill-development homes are available where some families choose to open their home to providing long-term care to adults with disabilities. Group homes are another option for families to consider. These homes are staffed by professionals to assist the residents with their basic needs. For those adults who need more intensive and constant supervision, institutional care is an option (NIMH, n.d.).

Mailick Selzer, Krauss, Shattuck, Orsmond, Swe, and Lord (2003) studied the symptoms of the Autism Spectrum Disorders (ASD) as the child progresses through adolescence and adulthood. Their research indicates although almost all of the participants met the criteria for an Autistic Disorder earlier in their childhood, just over half would have met the criteria with their current scores. It was also found that adolescents were more likely to improve in the reciprocal social interaction domain than adults. Adults were more likely to improve in the restricted, repetitive behaviors and interest domain. No significant difference was found between symptoms in the communication domain. Overall, a pattern of improvement from childhood to adolescence and adulthood was supported. This pattern of improvement is consistent
with past studies, but does not overshadow the fact that the majority of people diagnosed with ASD’s are affected throughout their lifetime (Mailick Selzer, et al., 2003).

Adults diagnosed with Pervasive Developmental Disorders typically continue to have difficulty with communication and social skills, however may be capable of obtaining employment with the right tools in place. Supervisors who are trained in working with people with disabilities, job training, encouragement, and a nurturing environment are tools which may assist the person in successfully maintaining employment (NIMH, n.d.).

Adults with Asperger’s Disorder often obtain a better understanding of their own strengths and weakness, enabling them to learn social skills and how to read social cues. Individuals with excellent memory and/or focused interests may find these skills beneficial to chosen career paths. Respected historical figures who have had symptoms of Asperger’s Disorder include: Wolfgang Amadeus Mozart, Albert Einstein, Marie Curie, and Thomas Jefferson (WebMD Health, 2004).

**Treatment Options**

There isn’t a treatment that cures any of the Pervasive Developmental Disorders, but treatment does assist people with PDDs develop to their full potential. Children with PDDs peak with therapy which is highly structured and specialized. There are educational and vocational programs for people with PDDs to help them with communication and decision-making skills. To improve overall function, the American Academy of Pediatrics recommends behavioral training and management, speech therapy, occupational therapy, physical therapy, medical management, community support, and parent training (WebMD Health, 2002).
Applied Behavior Analysis (ABA) is a method available for treatment and education of children diagnosed with Pervasive Developmental Disorders. This method of treatment has been proven effective in reducing inappropriate behaviors and increasing communication, learning, and social behaviors. Overall, the goal of ABA is to reinforce desirable behaviors and decrease undesirable ones (NIMH, n.d.).

Sensory integration is a form of treatment usually provided by occupational therapists. It is a form of treatment useful for children who engage in inappropriate responses to sensory stimuli. The sensory integration treatment consists of providing the child with various forms of sensory input resulting in the child’s relaxation. “The environment for sensory integrative therapy gives the child with Autism opportunities to swing, spin, slide, crawl, and perform other motor activities. These activities are designed to reorganize the child’s still flexible brain in a way that better integrates sensory input.” (Holmes, 1997, p.70). Using the sensory integration approach enables the child to be able to register and regulate sensory input more effectively. The world seems less threatening to them and they will be more apt to interact with other people and their surrounding environment (Holmes, 1997).

Medications may increase the person’s ability to learn and change behaviors. There are many herbal remedies, nutritional supplements, over-the-counter medications, and prescribed medications used with patients diagnosed with Pervasive Developmental Disorders. Herbal remedies and nutritional supplements lack research to determine their effectiveness. Some medications that have proven helpful for some children diagnosed with Pervasive Developmental Disorders include: antidepressants, psychostimulants, antipsychotic medications, and anticonvulsants. Antidepressants have been proven
effective to regulate the amount of Serotonin in the brain, which is involved in the transmission of messages from nerve cell to nerve cell. Antidepressants may also decrease irritability and repetitive movements and speech. In addition, antidepressants may increase social participation. Psychostimulants improve the brain’s capacity to focus. They may assist with over activity and/or distractibility. Antipsychotic medications have been implemented to assist in treating severe behavioral problems. These medications may assist with decreasing aggression, self-injurious behaviors, irritability, social withdrawal, over activity, and ritualistic behaviors. Most of the medications used to help lessen some of the symptoms by affecting the level of serotonin, a chemical in the brain responsible for mood. Anticonvulsants have been found to promote mood stabilization (Thorwarth Bruey, 2004).

Dietary interventions are sometimes used by parents as an additional way to provide treatment to their children. This intervention is based on assumptions that food allergies may cause PDDs and insufficiencies of specific vitamins or minerals may also be a cause. Gluten-free and casein-free diets have been found helpful by some parents. These diets are difficulty to follow due to their popularity in common foods such as milk and bread. Vitamin B6, A, and C supplements are thought to be effective, however results of research studies are mixed (NIMH, n.d.).

Auditory integration is often completed with children diagnosed with PDDs. They experience a hypersensitivity to sound that interferes with their ability to function in their daily lives. During this form of treatment, children wear headphones that play altered music, which is theoretically believed to reduce their auditory sensitivity.
However, no studies have confirmed auditory integration’s effectiveness (Hyman & Levy 2002).

Occupational therapists address a number of different aspects with children with Pervasive Developmental Disorders including: increasing independence in the activities of daily living, increasing play skills, increasing leisure exploration/participation, improving fine and gross motor skills, increasing muscle tone, promoting stability, improving balance, increase motor planning skills, decreasing self-abusive/self-stimulating behaviors, increasing body awareness, decreasing tactile defensiveness, increasing attention span, increasing understanding of social contexts, and decreasing dependence on routines.

**Parents’ Response to a PDD Diagnosis**

Initially, parents may feel relief after their child has been diagnosed with a Pervasive Developmental Disorder. The diagnostic process is a long and difficult one and finally parents receive answers for their children’s behaviors. Shortly after parents begin to feel relief they sometimes go through a range of emotions, commonly associated with the stages of grief documented by Kübler-Ross (Kübler-Ross, 1969). The parents may feel shock, depression, denial, guilt, shame, isolation, panic, anger, bargaining, and finally acceptance. A parent doesn’t necessarily feel all of these emotions or in this particular order. Shock usually happens when the initial diagnosis is made. The parents of a formerly typically developing child have been given the news that their child is not “normal”. A number of the parents’ expectations and plans must be altered when they discover their child has a PDD. Occasionally parents go through a period of denial and believe there must be a mistake in their child’s diagnosis. A period of guilt often follows
with parents believing they were somehow responsible. When a Pervasive Developmental Disorder is diagnosed, parents may imagine the worst. They begin to panic and wonder who should they tell, how do they tell them, and are they going to be able this unexpected situation? Anger sets in with many questions of “why”. “Why my child?”, “Why me?”, “Why, when we so carefully planned our pregnancy and did all the healthy things should my baby be burdened with this disability?” are common questions parents ask during their period of anger. Bargaining is when parents try to make a deal to make the diagnosis of their child go away. Finally, approach their child’s diagnosis with hope and acceptance. They have begun to understand Pervasive Developmental Disorders and accept their child (Satkiewicz-Gayhardt, et al., 2004).

**Siblings**

Siblings of children with Pervasive Developmental Disorders face a number of challenges. The sibling may be frightened by aggressive or self-abusive behaviors displayed by the child with the PDD. The typically developing sibling may feel as if he/she does not receive as much attention. Younger siblings may find they are acting in the role of an older sibling. Also teasing from other children their age is a large challenge siblings face. It is important for parents to teach every member of the family about the PDD that may be affecting a child in their family. It is important to encourage positive relationships between siblings, though it may be challenging.

The purpose of the study completed by Glasberg (2000) reported that terms such as Autism, Asperger’s, and PDDNOS were recognized by 79.4% of the participating siblings, with an increase in knowledge as age increased. However, 92.1% or the parents expected their children had previously heard and would recognize the diagnostic terms
listed above. It was determined that as the child participants’ age increased, so did their understanding of the Autism Spectrum Disorder and how it affected both them and their sibling. When children reached the adolescent age group, they began to imagine possible implications for the future. The younger children are more apt to describe what they can see, such as their sibling not being able to write. This study showed that parents make an effort to help their children understand Autism, but that what it all means isn’t really understood by the siblings. This illustrates the need for education for both parents and siblings on a level they are able to comprehend. If a parent doesn’t truly understand something, they will be unable to break it down to a form their children will be able to understand (Glasberg, 2000).

The purpose of this study done by Wood Rivers and Stoneman (2003) was to explore various factors that could possibly influence sibling relationships when one of the children is diagnosed with Autism. Previous review of existing literature has found conflicting results. Some of the studies found no difference in sibling relationships is one child has Autism, one found positive results, and another found the unaffected sibling to experience negative effects. Wood, Rivers, and Stoneman (2003) gathered information directly from the siblings and their parents to research the relationship between siblings when one child is diagnosed with Autism. Their findings showed that the siblings rated their relationship positively with their siblings with Autism, as did their parents. The quality increased when families sought out social supports. It was found that when the stress in the marriage increased, the quality of the sibling relationship declined. Overall, this study showed that a majority of typically developing siblings viewed their relationships positively with their sibling affected with Autism. Although, having a child
with a Pervasive Developmental Disorder in the family brings various challenges, most families do accommodate and adjust as needed. This reinforces the fact of having a child with a Pervasive Developmental Disorder will make the family face difficulties not otherwise expected with a typically developing child. However, these challenges can be overcome and have a positive effect on the family (Wood Rivers & Stoneman, 2003).

It is important to try to explain Pervasive Developmental Disorder to other children in the family. It is best to talk to them as soon as they are able to identify differences. Basically explaining their brother/sister is different from other people and things are harder for them. Children have a tremendous capacity for empathy when they are given information regarding their sibling’s disorder (Satkiewicz-Gayhardt, et al., 2004).

Siblings of children with a Pervasive Developmental Disorder will go through a range of emotions similar to those experienced by parents. Siblings greatly help the child with a PDD reach their full potential and often prove to be the child’s best friend and therapist (Satkiewicz-Gayhardt, et al., 2004).

**Conclusion**

The number of children being diagnosed with Pervasive Developmental Disorders is increasing. The cause is yet unknown, therefore the disorders are unable to be prevented. Research is being conducted in various areas to assist children and their families. Parents often struggle in managing the wide variety of symptoms and behaviors their children display and seek assistance or guidance to increase their child’s independence and ability to function better in daily life. There is a wide variety of treatment options available for parents to choose from in order to attempt to deal with
some of these issues. Children with Pervasive Developmental Disorders are frequently being diagnosed and treated by occupational therapists. These children exhibit sensory processing problems and have trouble functioning in their physical and social environments. Pervasive Developmental Disorders are a group of non-progressive, lifelong disorders that make children seem as though they are in a world of their own. With the further advancements of medications and treatment approaches, maybe someday they will let everyone into their world.
Cumulative References


Presentations
Learning About Pervasive Developmental Disorders

By: Krystal Cook, MOTS
Pervasive Developmental Disorders (PDDs)

- A group of disorders involving delays in many basic skills
  - Impairments in social interaction
  - Impairments in verbal and nonverbal communication
  - Impairments in imaginative play
  - Repetitive actions
  - Limited number of interests
Pervasive Developmental Disorder Spectrum

- Autism
- Asperger’s Disorder
- Rett’s Disorder
- Childhood Disintegrative Disorder (CDD)
- Pervasive Disorder Not Otherwise Specified (PDDNOS)
Typical Characteristics of Children Diagnosed with PDDs

- Abnormal responses to sensory stimuli
- Difficulty with communication
- Difficulty with social interaction
- Unusual ways of playing with toys or other objects
- Difficulty adjusting to changes in routine
- Repetitive body movements
- Temper tantrums
- Difficulty sleeping
- Fearfulness or anxiety
Autistic Savants

- Term used to describe the children with exceptional skills in specific areas

- 10% of children diagnosed with PDDs

- Have exceptional skills in math, drawing, music, memory, etc.
Diagnosis
Diagnosis

- A difficult task

- There are no definitive diagnostic tests
Diagnosis

- Review of past and current behaviors
- Ruling out other disorders
The Diagnostic Process

- Developmental screenings are typically completed during routine check-ups, or if a parent becomes concerned.

- There are an assortment of screening instruments used to differentiate children with PDDs from other groups of disorders.
Screenings

- Do not provide a diagnosis
- Assessment to determine if a referral is necessary
- If the screening is indicative of a PDD, further evaluation is completed
Diagnosis

- There is not one specific test to determine if a child has a Pervasive Developmental Disorder.

- If a health professional discovers any prominent developmental delays, they should be further evaluated.
Communication Delays

- no babbling, point, or other gestures by 12 months
- no single words by 16 months
- no two word spontaneous phrases by 24 months, with the exception of repeated phrases
- any loss of any language or social skills at any age
Is it important to give a child a diagnosis?

- Yes!

- A diagnosis:
  - gives the parents a better understanding of their child’s symptoms and needs
  - Guides appropriate treatment
  - Enables parents to find other parents/professionals with information on their child’s diagnosis and to establish a social support system
  - Aids in ability to receive funding
Etiology

What is causing these disorders?
The exact cause of any of the Pervasive Developmental Disorders are not know.
Etiology

- Parental personality or child-rearing practices DO NOT cause Pervasive Developmental Disorders
Etiology

Possible causes

- genetic factors
- infectious diseases
- neurobiological abnormalities
- allergies
- prenatal, perinatal, neonatal trauma
- neurochemical abnormalities
Genetics

- Studies have shown PDDs (with the exception of Rett’s Disorder) are not linked to a single dominant or recessive gene.
Infectious Diseases

- PKU
- Encephalitis
- Meningitis
- Rubella
- CMV
Allergies

- fungal infections
- virus infections
- Vaccinations
- various foods
MMR vaccination

- Measles, mumps, rubella vaccination has been a recent cause for concern
- There has been an increase in the diagnoses of various PDDs, along with an increase in the distribution of the MMR vaccine
- No proof has been found to date indicating there is a correlation between the two
Further research is being conducted in all areas to determine the causes of Pervasive Developmental Disorders
Prognosis

- Certain aspects are indicators of a more favorable future for children with a Pervasive Developmental Disorder.
Indicators of a More Favorable Future

- Initial IQ over 60
- Some spontaneous speech by age six
- Less severe symptoms
- More passive behavioral manner
Unfavorable Indicators

- Development of a seizure disorder
- Inability to play appropriately with toys
- Living in an unstable home environment
Prognosis

- Two-thirds of children with PDDs will not be able to lead independent adult lives
Adolescence

- Is accompanied by stress, confusion, and maturing sexuality
- Some behaviors may improve, some may become worse
- A time when children become more aware of their peers
Decision Time

- Public schools provide services until 22 years of age
- Then the family is faced with a number of challenges
Challenges

- Finding living arrangements
- Finding possible employment
- Finding programs and/or facilities that will support the further development of their child
Adulthood

- Improvements may be noted in the areas of restricted, repetitive behaviors and interest domain
Possible Living Arrangements

- Some adults with PDDs are successfully able to live alone with assistance with major issues
- Government funds available to care for child at home
- Information about these funds is available from the Social Security Administration
- Foster homes and skill-development homes
- Institutions
Childhood Disintegrative Disorder (CDD)
CDD is also known as:

- Heller’s syndrome
- dementia infantilis
- disintegrative psychosis
Childhood Disintegrative Disorder

- Typically develop normally for the first two years, then regression begins

- A longer period of normal development assists in differentiating CDD from Rett’s Disorder
Areas of Functioning Affected by CDD

- Language
- Social skills
- Motor skills
- Play
- Bowel and bladder control
- Unfortunately severe mental retardation usually accompanies this disorder
Childhood Disintegrative Disorder

- Majority are boys, however male to female ratio is unknown

- Rare disorder: diagnosed in 5/10,000 births
Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)
Pervasive Developmental Disorder Not Otherwise Specified

- Diagnostic category for children who do not meet the criteria for any of the above disorders
- Are social, but have significant problems with communication and play
- None of symptoms are as severe as the other disorders
Treatment Options
Unfortunately, there isn’t a treatment that cures any of the Pervasive Developmental Disorders.

But treatment does assist people with Autism develop to their full potential.
Applied Behavior Analysis

- method available for treatment and education of children diagnosed with PDDs
- has been proven effective in reducing inappropriate behaviors and increasing communication, learning, and social behaviors
- the goal of ABA is to reinforce desirable behaviors and decrease undesirable ones
Sensory Integration

- Usually provided by occupational therapists
- Useful for children who engage in inappropriate responses to sensory stimuli
- Enables the child to better be able to register and regulate sensory input
Medications

- may increase the person’s ability to learn and change behaviors

- There are some medications that have proven helpful for some children diagnosed with PDDs
Medications

- Antidepressants
- Psychostimulants
- Antipsychotic medications
- Anticonvulsants
Antidepressants

- May decrease irritability
- May decrease repetitive movements and speech
- May increase social participation
Psychostimulants

- Improve the brain’s capacity to focus
- Assist with distractibility and/or over activity
Antipsychotic Medications

- Implemented to assist in treating severe behavioral problems
- May assist in decreasing:
  - aggression
  - self-injurious behaviors
  - irritability
  - social withdrawal
  - over activity
  - ritualistic behaviors
Anticonvulsants

- Have been found to promote mood stabilization
Dietary Interventions

- Sometimes used by parents as an additional method of treatment

- Based on assumptions that food allergies may cause PDDs and insufficiencies of specific vitamins or minerals may also be a cause

- Gluten-free and casein-free diets

- Vitamin B6, A, and C supplements
Auditory Integration

- Completed to decrease hypersensitivity
- Wear headphones that play altered music
- No studies have proven its effectiveness
Occupational Therapy

- Work with children on an assortment of items:
  - increasing independence in the activities of daily living
  - increasing play skills
  - increasing leisure exploration/participation
  - improving fine and gross motor skills
  - increasing muscle tone, promoting stability
  - improving balance, increase motor planning skills

- decreasing self-abusive/self-stimulating behaviors
- increasing body awareness
- decreasing tactile defensiveness
- increasing attention span
- increasing understanding of social contexts
- decreasing dependence on routines
Assistive Communication

AAC
Augmentative
Alternative
Communication
Communication

- Ability to select words and organize them into sentences
- Rules = language and communication skills
- Through speech and through writing
- Inability to communicate is a communication disorder
Unaided Communication

- Unaided: any communication that requires only the person’s own body
The support of language through means other than the traditional mode

Any communication that requires something other than the person’s own body, such as a pen, letter communication board, typewriter, etc.

May include

- sign language
- communication boards
- electronic and computer technology
AAC is important because:

- It improves quality of life
- Improves personal relationships by increasing interaction
- Increases independence
- Satisfies basic needs
How would you feel if you were not able to communicate with staff/peers for the rest of the day?
Impact of communication disorders

- Inability to communicate
- Strained social relationships
- Inadequate education
- Frustration
- Isolation
- Dependency
- Low self-esteem
Etiologies of severe communication disorders

- Cognitive Challenges
- TBI
- Dysarthria
- Aphasia
- Degenerative Disease
- Apraxia
- Laryngectomy
- Physical Disabilities
- Specific Language Impairments
Major Causes of Inability to Speak or Write

- Degenerative diseases
  ALS, TBI, Strokes
- Neuromuscular conditions
  Cerebral palsy
Speech Production Aids

- Aids for Laryngectomies
- Voice Amplification
- Speech Training Aids
- Voice Recognition
AAC Systems

Technologies that provide a means for written and spoken communication
AAC Systems

**Low Technology**
- gestures
- sign language
- alphabet boards
- communication notebooks
- language boards
- eye gaze boards

**High Technology**
- simple electronic
- complex multi-level systems
AAC Systems

- Manual
  - Paper letter boards

- Electronic
  - Computers
# Types

<table>
<thead>
<tr>
<th>Dedicated</th>
<th>Nondedicated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serves one purpose</td>
<td>Computer based programs to use same system for multiple applications</td>
</tr>
<tr>
<td>- the production of verbal speech</td>
<td>- AAC</td>
</tr>
<tr>
<td></td>
<td>- word processing</td>
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<td></td>
<td>- environmental control</td>
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<td></td>
<td>- written communication</td>
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</tbody>
</table>
Types of Speech

Digitized
- Recorded natural speech
- Amount available dependent upon system capacity
- More acceptable to younger learner

Synthetic
- Artificially generated speech
- Multiple voices
- Amount available dependent upon system capacity
Selection

**Direct Selection**
User points to selection of applies pressure to activate a single space or a key

**Scanning Modalities**
User can make a selection with a switch as the system scans choices
Selection Set

**Ionic**
- Picture based symbol system
- Can be used with preliterate communicators

**Graphic**
- User typed text that is synthetically voiced
- User must have some level of reading and spelling
What is being said here?
Many people with disabilities have begun to use email to communicate with friends, business associates, and organizations.

Email allows composition at a slower speed because the reader reads the message after composition is completed.

Can communicate without someone else being present.

The internet provides access to various information, chat rooms for support, opportunities for reading and writing.
Learning Tools

- Language Learning Tool
- Augmented Literacy Instruction
- Cognitive Aids

Your answers to study question # 6
Assessment for AAC

- Background Information
- Needs Analysis
- Capabilities Assessment
- Observation
- Technology Access
- Cognitive Status
- Speech
- Language
- Symbol Representation
- Literacy
- Sensory/Perceptual
- Device Selection and Evaluation
Recommendation for the AAC System

- Selection of a control interface
- Determine cognitive and language skills
- Relating consumer goals and skills to device characteristics
Implementation

- Each user needs to be trained to use their communication system based on the abilities they currently have
- Basic Skills
- Aided Language Stimulation
- Literacy
Case Study

- Heidi is a doctoral student studying English at a major university. She has cerebral palsy which limits her ability to speak and use her hands for writing.
  - How can she compose her writing assignments?
  - How can she participate in class discussions?
  - How can she communicate with friends, professors, classmates on a daily basis when telephone use is not an option?
Future Trends and Needs

- An increased awareness of AAc use in the areas of autism, strokes, and geriatric populations
- Increased awareness of technology available
- Students are being mainstreamed into their public schools
In conclusion........

- Augmentative and alternative communication systems serve needs for both writing and conversation for individuals with difficulties in these areas
- Thoughtful assessment, careful training, and thorough follow-through are essential to effective AAC intervention
Resources

THE END
Resources

Books


Internet Sources

Asperger Syndrome Information and Support
http://www.aspergerssyndrome.org
This website contains articles about social skills, education, diagnosis, etc related to Asperger's Syndrome. It includes message boards for parents, people diagnosed with Asperger's Syndrome, and professionals. In addition, lists of private schools and camps.

The Center for the Study of Autism
http://www.autism.org
This website contains various information regarding related disorders, interventions, interviews with parents, siblings, and links to other related resources.

Dr Koop
http://www.drkoop.com/
This website provides definitions of Pervasive Developmental Disorders, lists of alternative names, symptoms, signs and tests, diagnostic criteria, causes, incidence, and risk factors.
Enabling Devices
http://enablingdevices.com
This website offers a variety of toys for special children. The toys focus on the needs of children with various disabilities. Catalogs can be browsed online or mailed to you free of charge.

Federation for Children with Special Needs
http://www.fcsn.org
The Federation is a center for parents to work together on behalf of children with special needs and their families. This site includes information regarding education and special needs, health care, publications and resources, and early childhood development information.

Mayo Clinic
http://www.mayoclinic.com
This website contains information regarding signs and symptoms, causes, when to seek medical advice, screening and diagnosis, treatment, and coping skills in relation to Pervasive Developmental Disorders.

National Institute of Mental Health
This website contains information from the National Institute of Mental Health. Information on this website includes: PDD topic overview, rare Autism Spectrum Disorders, symptoms, problems, diagnosis, available aids, treatment options, research, and information on adults diagnosed with an Autism Spectrum Disorder.

WebMD
http://www.webmd.com/
This website contains topic overviews of PDDs including information on symptoms, exams and tests, treatment overview, home treatment, and other places to get help.

Associations/Networks/Organizations
Autism Research Institute
4182 Adams Ave
San Diego, CA 92116
1-619-281-7165
Dr. Rimland, the founder of the Autism Research Institute, is the father of an adult son with Autism. Dr. Rimland publishes a quarterly newsletter containing information concerning the latest medical findings in the treatment and research of Autism and it’s related disorders.
Autism Resource Network
Cherri Saltzman, Director
5123 Westmill Road
Minnetonka, MN 55345
1-612-988-0088

Founded by parents of a child with Autism, this non-profit information agency publishes a quarterly newsletter and operates a large mail-order book store with over 100 Autism-related titles. It also offers note cards, t-shirts, sweatshirts, and totes in support of people with Autism.

Autism Society of America
27910 Woodmont Avenue, Suite 650
Bethesda, MD 20814-3015
1-800-3-AUTISM
http://www.autism-society.org

The Autism Society of America is a national organization that provides a variety of information that will refer you to the closest ASA chapter in your area and offer extensive information concerning an assortment of information relating to Autism/PDDs. (annual membership fee is $25)

CAN (Cure Autism NOW)
5225 Wilshire Blvd., Suite 503
Los Angeles, CA 90036
1-213-549-0500
http://www.canfoundation.org

CAN is a parent founded organization that funds research on biological treatments for autism. The web site includes information on various types of research on Autism from 1966 to present.

The Division for Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)
310 Medical School Wing E
CB #7180
The University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7180
1-919-966-2174

This program provides newsletters, bookstores, diagnostic evaluation, treatment plans, training, and consultation for people with Autism.

Families for Early Autism Treatment (FEAT)
PO Box 255722
Sacramento, CA, 95865-5722
1-916-843-1536
http://www.feat.org

This organization is devoted to the advocacy, education, and support of families and professionals.
International Rett Syndrome Association (IRSA)
9121 Piscataway Rd.
Clinton, MD 20735
1-800-818-RETT
http://www.rettsyndrome.org
IRSA is a national organization for families affected by Rett’s Syndrome. It provides information, referrals, encourages public awareness.

National Information Center for Children and Youths with Disabilities
Box 1492
Washington, DC 20013-1492
1-800-999-5599
Assists you with locating special educational programs, services, and support.
Information provided is free.

National Parent Network on Disabilities
1727 King St., Suite 305
Alexandria, VA 22314
1-703-684-6763
This network will give you access to local parent training and information centers.
Parent Handouts
Learning About Pervasive Developmental Disorders
By: Krystal Cook, MOTS

Pervasive Developmental Disorders (PDDs)
- A group of disorders involving delays in many basic skills
  - Impairments in social interaction
  - Impairments in verbal and nonverbal communication
  - Impairments in imaginative play
  - Repetitive actions
  - Limited number of interests

Pervasive Developmental Disorder Spectrum
- Autism
- Asperger’s Disorder
- Rett’s Disorder
- Childhood Disintegrative Disorder (CDD)
- Pervasive Disorder Not Otherwise Specified (PDDNOS)

Typical Characteristics of Children Diagnosed with PDDs
- Abnormal responses to sensory stimuli
- Difficulty with communication
- Difficulty with social interaction
- Unusual ways of playing with toys or other objects
- Difficulty adjusting to changes in routine
- Repetitive body movements
- Temper tantrums
- Difficulty sleeping
- Fearfulness or anxiety

Autistic Savants
- Term used to describe the children with exceptional skills in specific areas
- 10% of children diagnosed with PDDs
- Have exceptional skills in math, drawing, music, memory, etc.
Autism

Autism
- Most commonly diagnosed PDD
- Sometimes referred to as early infantile Autism, Kanner’s Autism, or childhood Autism

History of Autism
- In the early 18th century, medical texts began having definitions of what is now believed to be Autism
- 1911 the term Autism was first used by Eugene Blueler
- 1943 Leo Kanner first described the disorder
- 1960’s advances in treatment
- 1977 first definition of Autism published
- 1980 DSM definition of Autism for the first time

Autism
- Disorder of the brain that interferes with normal development in the areas of social interaction and communication skills
- No congenital signs
- Appear to develop normally until 12-24 month when symptoms of Autism start to develop
- Parents become concerned when their child doesn’t babble, doesn’t like to be held, and appears to be deaf

Autism
- 4-5 x more common in males than females
- Occurs between 2-20/10,000 births
- Lifelong developmental disability

Five General Characteristics of Autism
- Failure to develop normal socialization
- Disturbances in speech, language, and communication
- Abnormal relationships to objects and events
- Abnormal responses to sensory stimuli
- Developmental delays and differences

Failure to Develop Normal Socialization
- Appears to be the most noticeable characteristic of Autism
- Don’t interact with others appropriately, normally, or even at all
- Prefer to play alone
- Don’t display normal facial expressions or understand those of others
- Extreme difficulty expressing emotion and difficulty understanding others’ emotions
- Perceived to be living in a world of their own

**Language**
- Some children display echolalia
- Child’s voice may be flat or monotonous
- May not be able to control pitch or volume
- Difficulty learning to talk
- Difficulty with conversations
Asperger’s Disorder

Asperger’s Disorder
■ Relatively new diagnosis
■ 5 x more common in males than females
■ Reported prevalence ranges from 3-36 out of 1000 births

Symptoms of Asperger’s Disorder
■ lack of social skills
■ dislike changes in routines
■ appear to lack empathy
■ speech may be flat and difficult to understand
■ may have a formal style of speech that is advanced for their age
■ avoid eye contact
■ heightened sensitivity

Symptoms of Asperger’s Continued…. 
■ unusual facial expressions or postures
■ preoccupation with one or a few interests
■ talk a lot about one favorite subject
■ delayed motor movement, clumsiness
■ may have advanced rote memorization and/or math skills

Asperger’s Disorder vs. Autism
■ Considered a sub-type of Autism
■ Differentiated by a later onset and unaffected speech
■ Sometimes referred to “high functioning Autism”
■ Tend to function better in daily life
Rett’s Disorder

History of Rett’s Disorder
- first identified in 1966 by Andreas Rett, an Austrian physician

Rett’s Disorder
- Normal development until approximately 18 months, when parents notice a change in their child’s behavior
- Usually associated with severe to profound mental retardation
- Display a slowing in head growth which results in a plateau of the brain

Rett’s Disorder
- Rare neurodegenerative disorder
- Genetic
- Caused by a defective gene

Rett’s Disorder
- Rett’s Disorder occurs in children from every racial, ethnic, intellectual, and socioeconomic background
- Occurs in 1:15,000 female births in the United States
- Exclusive to females

Symptoms of Rett’s Disorder
- Autistic-like behaviors
- breathing irregularities
- feeding and swallowing difficulties
- growth retardation
- impaired control of voluntary movements
- episodes of uncontrolled electrical activity of the brain resulting in seizures

Identifiable Behavior of Rett’s Disorder
- Hand-wringing or hand-washing
**Childhood Disintegrative Disorder (CDD)**

CDD is also known as:
- Heller’s syndrome
- dementia infantilis
- disintegrative psychosis

**Childhood Disintegrative Disorder**
- Typically develop normally for the first two years, then regression begins
- A longer period of normal development assists in differentiating CDD from Rett’s Disorder

**Areas of Functioning Affected by CDD**
- Language
- Social skills
- Motor skills
- Play
- Bowel and bladder control
- Unfortunately severe mental retardation usually accompanies this disorder

**Childhood Disintegrative Disorder**
- Majority are boys, however male to female ratio is unknown
- Rare disorder: diagnosed in 5/10,000 births
Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)

Pervasive Developmental Disorder Not Otherwise Specified
- Diagnostic category for children who do not meet the criteria for any of the above disorders
- Are social, but have significant problems with communication and play
- None of symptoms are as severe as the other disorders
**Etiology**

*What is causing these disorders?*

- The exact cause of any of the Pervasive Developmental Disorders are not known.

**Etiology**

- Parental personality or child-rearing practices DO NOT cause Pervasive Developmental Disorders

**Possible causes**

- genetic factors
- infectious diseases
- neurobiological abnormalities
- allergies
- prenatal, perinatal, neonatal trauma
- neurochemical abnormalities

**Genetics**

- Studies have shown PDDs (with the exception of Rett’s Disorder) are not linked to a single dominant or recessive gene

**Infectious Diseases**

- PKU
- Encephalitis
- Meningitis
- Rubella
- CMV

**Allergies**

- fungal infections
- virus infections
- vaccinations
- various foods

**MMR vaccination**

- Measles, mumps, rubella vaccination has been a recent cause for concern
- There has been an increase in the diagnoses of various PDDs, along with an increase in the distribution of the MMR vaccine
- No proof has been found to date indicating there is a correlation between the two

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- A difficult task
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The Diagnostic Process

- Developmental screenings are typically completed during routine check-ups, or if a parent becomes concerned
- There are an assortment of screening instruments used to differentiate children with PDDs from other groups of disorders

Screenings

- Do not provide a diagnosis
- Assessment to determine if a referral is necessary
- If the screening is indicative of a PDD, further evaluation is completed

Diagnosis

- There is not one specific test to determine if a child has a Pervasive Developmental Disorder
- If a health professional discovers any prominent developmental delays, they should be further evaluated

Communication Delays

- no babbling, point, or other gestures by 12 months
- no single words by 16 months
- no two word spontaneous phrases by 24 months, with the exception of repeated phrases
- any loss of any language or social skills at any age

Is it important to give a child a diagnosis?

- Yes!
- A diagnosis:
  - gives the parents a better understanding of their child’s symptoms and needs
  - Guides appropriate treatment
  - Enables parents to find other parents/professionals with information on their child’s diagnosis and to establish a social support system
  - Aids in ability to receive funding
**Prognosis**

- Certain aspects are indicators of a more favorable future for children with a Pervasive Developmental Disorder

**Indicators of a More Favorable Future**
- Initial IQ over 60
- Some spontaneous speech by age six
- Less severe symptoms
- More passive behavioral manner

**Unfavorable Indicators**
- Development of a seizure disorder
- Inability to play appropriately with toys
- Living in an unstable home environment

**Prognosis**
- Two-thirds of children with PDDs will not be able to lead independent adult lives

**Adolescence**
- Is accompanied by stress, confusion, and maturing sexuality
- Some behaviors may improve, some may become worse
- A time when children become more aware of their peers

**Decision Time**
- Public schools provide services until 22 years of age
- Then the family is faced with a number of challenges

**Challenges**
- Finding living arrangements
- Finding possible employment
- Finding programs and/or facilities that will support the further development of their child

**Adulthood**
- Improvements may be noted in the areas of restricted, repetitive behaviors and interest domain
**Possible Living Arrangements**

- Some adults with PDDs are successfully able to live alone with assistance with major issues
- Government funds available to care for child at home
- Information about these funds is available from the Social Security Administration
- Foster homes and skill-development homes
- Institutions
**Parents’ Response to a PDD Diagnosis**

- Parents sometimes go through a range of emotions, commonly associated with the stages of grief documented by Kübler-Ross
  - Shock
  - Depression
  - Denial
  - Guilt
  - Shame

**Shock**
- Usually happens when the initial diagnosis is made
- Expectations and plans change

**Denial**
- Believe there must be a mistake

**Guilt**
- A period of guilt often follows
- Parents feel as if they are to blame

**Panic**
- Parents begin to imagine the worst
- They begin to wonder who should they tell, how do they tell them, and are they going to be able this unexpected situation

**Anger**
- Anger sets in with many questions of “why”
  - “Why my child?”
  - “Why me?”
  - “Why, when we so carefully planned our pregnancy and did all the healthy things should my baby be burdened with this disability?”

**Bargaining**
- When parents attempt to make a deal to make their child’s diagnosis go away

**Hope and Acceptance**
- Parents begin to understand PDDs and begin to accept their child
**siblings**

- Face a number of challenges
- Sibling may be frightened by aggressive or self-abusive behaviors displayed by the child with the PDD
- Feel as if they aren’t getting enough attention
- Teasing from other children

**siblings**

- It is important to explain PDDs to siblings
- Talk to them as soon as they are able to identify differences
- Siblings help children reach their full potential
- Often prove to be the child’s best friend
Treatment Options

- Unfortunately, there isn’t a treatment that cures any of the Pervasive Developmental Disorders
- but treatment does assist people with Autism develop to their full potential.

Applied Behavior Analysis

- method available for treatment and education of children diagnosed with PDDs
- has been proven effective in reducing inappropriate behaviors and increasing communication, learning, and social behaviors
- the goal of ABA is to reinforce desirable behaviors and decrease undesirable ones

Sensory Integration

- Usually provided by occupational therapists
- Useful for children who engage in inappropriate responses to sensory stimuli
- Enables the child to better be able to register and regulate sensory input

Medications

- may increase the person’s ability to learn and change behaviors
- There are some medications that have proven helpful for some children diagnosed with PDDs

Medications

- Antidepressants
- Psychostimulants
- Antipsychotic medications
- Anticonvulsants

Antidepressants

- May decrease irritability
- May decrease repetitive movements and speech
- May increase social participation

Psychostimulants

- Improve the brain’s capacity to focus
- Assist with distractibility and/or over activity
Antipsychotic Medications
- Implemented to assist in treating severe behavioral problems
- May assist in decreasing:
  - aggression
  - self-injurious behaviors
  - irritability
  - social withdrawal
  - over activity
  - ritualistic behaviors

Anticonvulsants
- Have been found to promote mood stabilization

Dietary Interventions
- Sometimes used by parents as an additional method of treatment
- Based on assumptions that food allergies may cause PDDs and insufficiencies of specific vitamins or minerals may also be a cause
- Gluten-free and casein-free diets
- Vitamin B6, A, and C supplements

Auditory Integration
- Completed to decrease hypersensitivity
- Wear headphones that play altered music
- No studies have proven it’s effectiveness

Occupational Therapy
- Work with children on an assortment of items:
  - increasing independence in the activities of daily living
  - increasing play skills
  - increasing leisure exploration/participation
  - improving fine and gross motor skills
  - increasing muscle tone, promoting stability
  - improving balance, increase motor planning skills
  - decreasing self-abusive/self-stimulating behaviors
  - increasing body awareness
  - decreasing tactile defensiveness
  - increasing attention span
  - increasing understanding of social contexts
  - decreasing dependence on routines
Siblings
Siblings

- Face a number of challenges
- Sibling may be frightened by aggressive or self-abusive behaviors displayed by the child with the PDD
- Feel as if they aren’t getting enough attention
- Teasing from other children
Siblings

- It is important to explain PDDs to siblings
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Chapter Four References


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CHAPTER V
SUMMARY

The need was identified for a parental education course that is client-centered and gives the parents the most beneficial and worthwhile information. A parental education course entitled “Learning About Pervasive Developmental Disorders” was developed to meet the need of parents and caregivers desiring information about their children. The literature was reviewed to determine the types of information parents wanted from education courses. This information was used to construct a client-centered course. Literature results regarding how to effectively teach adults and important information concerning Pervasive Developmental Disorders were also used to successfully reach the mission of this class: to assist parents in gaining knowledge to begin to understand their child and provide better care. The course is occupational therapy based and provides information on topic areas of interest to parents. It was determined occupational therapy is a discipline with adequate knowledge to prepare and teach a course of this type.

The course has been developed so it is ready for use. All of the crucial elements needed to successfully teach the education course are included in the product. It is recommended this course be taught to parents/caregivers of children with Pervasive Developmental Disorders in a two part session with a maximum of eight participants. Further, it is recommended that information be gathered from the parents prior to the beginning of the course in order to identify the material the parents desire information on. Future research may contribute to the course information by providing new advances in
treatment ideas, causes, etc. To further develop the education course computer-based courses, a one day Saturday course, and determining a set monthly schedule for the course may be beneficial.

Limitations of this project include lack of information regarding financial support for the intervention, unresolved issues related to care for other children in the families, and a lack of opportunity for both parents to attend the session. Further, there has been a lack of pilot testing to gain parents’ perspectives on the education course.

Recommendations for the future include seeking grant funding from Autism-related groups, such as Autism Resource Network, to assist with the cost of materials and staff to teach the course; advertising volunteer hours for pre-occupational therapy students for babysitting children during the course; offering occupational therapists continuing education for teaching the course is a way of reimbursing the OT for his or her time. The therapist could use these activities to accumulate professional development units necessary for continuing National Board for Certification in Occupational Therapy. Having the means to video-tape the course session will allow other family members the ability to learn information from the class. In addition, incorporation of participating parents’ feedback will be used to further develop this program’s client-centeredness.
References


