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Fotonovelas: A Parent Resource and Education Guide for Underserved Hispanic Families with Autism in Marin County

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Fotonovelas: A Parent Resource and Education Guide for
Underserved Hispanic Families with Autism in Marin County

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A Thesis in Fulfillment of the
Requirements for the Degree
Masters of Science in Occupational Therapy
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This thesis, written under the direction of the candidate's thesis advisor and approved by the Chair of the Master's program, has been presented to and accepted by the Faculty of the Occupational Therapy department in partial fulfillment of the requirements for the degree of Occupational Therapy. The content and research methodologies presented in this work represent the work of the candidate alone.

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Abstract

The current estimated prevalence of autism in the United States is 1 out of 88 children, up from 2006 when the estimated prevalence of autism was 1 out of 110 (Centers for Disease and Prevention, 2012). Increasing numbers are a major concern because there is a greater need for services for individuals with autism. According to Kidsdata (2010), approximately 5.7% of Marin County of California's population of children has a diagnosis of autism.

The Hispanic community forms the largest minority group in Marin County, consisting of 15.5% of the population (US Census Bureau, 2010). This community was the target underserved population for this project. The purpose of this project was to create a parent resource and education guide for the Marin Autism Collaborative in a fotonovela format. A fotonovela is a Spanish language photo-book that tells a dramatic storyline (Flora, 1980). A fotonovela can be an effective tool in educating the Hispanic community in Marin County about autism (Unger, Molina, & Baron, 2009). The project bridges the gap in autism awareness within this hard to reach, underserved population by providing an education-resource guide in a culturally appropriate format. A Likert scale survey of the fotonovela was given to families that provided their stories, occupational therapists, and other professionals to evaluate the fotonovela. Overall, the results of the surveys were positive.

Introduction

Autism Spectrum Disorders (ASD) are a group of pervasive neurodevelopmental disorders that affect many children and persist throughout their lifetime (Center for Disease Control and Prevention [CDC], 2012). ASD is a collective term which includes Pervasive Developmental Disorder-Not Otherwise Specified, Asperger's Disorder, and Autistic Disorder. ASD can be diagnosed as early as 18 months, and children are commonly diagnosed by the age of 3 (CDC, 2012).

According to the CDC (2012), the estimated prevalence of autism in the United States is 1 in every 88 children. Boys are 4 to 5 times more likely to be diagnosed with autism than girls. This neurodevelopmental disorder has shown no known boundaries with regards to racial, ethnic, or socioeconomic groups (CDC, 2012).

In 2005, 4.3% of California's population was diagnosed with autism (Kidsdata.org, 2010). By 2010, the prevalence had doubled to 8.8% of the population (Kidsdata.org, 2010). In 2005, in Marin County, 2.9% of children were diagnosed with autism and by 2010 the percentage of the population diagnosed with autism nearly doubled to 5.7% (Kidsdata.org, 2010). The reason for the increase in diagnosis of this disorder is unknown. However, the increasing prevalence is a major concern because there is a greater need for services for individuals with autism.

An occupational therapist's role is to promote health and participation for individuals, groups and populations to enhance occupational performance (American Occupational Therapy Association [AOTA], 2008). ASD impacts a child's occupations including sleep, play, school-based occupations, social participation, and feeding (American Psychiatric Association [APA], 2000). Families of children with autism are

also affected by the diagnosis. Parents have an increased risk of depression, increased stress on a marriage, difficulties maintaining their social life, and financial issues.

Siblings may also feel the impact of a diagnosis of autism in the family (Bradford, 2010).

While all families of children with autism face a variety of issues, some families encounter additional challenges because they are unable to access appropriate health care services for their child. Within the health care field these families are referred to as “underserved.” The factors that contribute to their limited health care access include: socioeconomic status (SES), insurance status, race/ethnicity, language barriers, and immigration status (Lykens, Fulda, Bae, & Singh, 2009; Newacheck, Hung, & Wright, 2002; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Families with low socioeconomic status (SES) have financial barriers impacting their ability to afford health care insurance. Limited or inconsistent access to health care or insurance can cause a decrease in appropriate diagnoses and services for CSHCN (Raphael et al., 2009).

Race and ethnicity both influence the ability of a family with a child with a disability to access medical care and influence communication with health care providers (Blumberg, Read, Avila, & Bethell, 2010; Coker, Rodriguez, & Flores 2010; Flores & Nugi, 2006; Raphael et al., 2009). In addition, studies have found that health care providers lack cultural awareness and sensitivity when providing care to children with special healthcare needs who come from ethnic families (Coker et al., 2010). Language barriers can interfere with a parent’s ability to advocate effectively for their child. This results in children with special health care needs (CSHCN) not receiving necessary medical services (Blumberg et al., 2010; Stevens & Shi, 2003; Sun, Sangweni, Butts, & Merlino, 1998).

There are many different “underserved” communities that exist in Marin County. The focus of this project is on the underserved Hispanic community of Marin County, as they are the largest minority group at 15.5% of the population (U.S. Census Bureau, 2011). Research also suggests that when comparing all ethnic groups, Hispanic children reported the lowest numbers of consistent health insurance coverage (Raphael, Guadagnolo, Beal, & Giardino, 2009). This project’s goal was to provide the underserved Hispanic population with knowledge about autism and appropriate resources to promote occupational participation in their context.

A discussion with a local county autism agency determined that an informative resource guide was necessary for the underserved Hispanic population of Marin County. A Spanish language photo-book, also known as a “fotonovela” is a culturally effective format to use to help communicate information to the Hispanic community (Flora, 1980; Carrillo and Lyson 1983). At the start of this project there were no fotonovelas that presented general information and resources about autism. We hope the tool will fill a gap and will be effective in providing information about ASD to the Hispanic community in Marin County.

Literature Review

This literature review will provide an overview of issues related to autism. First we will discuss the occupational challenges that children with autism encounter. Next, we will review the challenges families face when they raise a child with autism. Finally, we will cover the challenges and disparities that underserved communities experience when accessing health care services.

Occupational Challenges Faced by Children with Autism

Children with autism encounter challenges in multiple areas of occupation; Social participation, school-based occupations, feeding, sleep, and play (APA, 2000). These children face challenges in these areas because of difficulties with language use, social skills, sensory processing, and behavioral regulation (APA, 2000).

Children with autism face occupational challenges with social participation (APA, 2000). Children with autism have problems with activities that require social attention, responding to environmental stimuli, recognizing emotions of others, and speech (Dawson, Nektziff, Osterling, Rinaldi, & Brown, 1998; Dawson et al., 2004; Macintosh & Dissanayake, 2006; Phillip et al., 2010). For example, children with autism may have difficulties providing direct eye contact (Dawson et al., 1998; Phillip et al., 2010). Eye contact is important because it is a social skill that is needed to help communicate to other people and express emotions. Eye contact is one way a person can interest, respect, and appreciation to others during communication (Boraston, Corden, Miles, Skuse, & Blakemore, 2008). Children with autism also may not consistently respond to their own name and environmental stimuli such as hand clapping (Dawson et al., 1998; Dawson et al., 2004). Environmental stimuli are socially important because they are communication cues. For instance, a child with autism may not respond to peer's attempt to initiate interaction. Children with autism also have trouble accurately responding and recognizing emotions. For example, if a person is crying the child might not be able to acknowledge that the person is sad. Finally, children with autism also show language deficits. They often remain nonverbal or have a limited amount of speech for their chronological age (Landa & Goldberg, 2005). Limited and delayed expressive language

can interfere with effective communication with their parents, teachers, and interactions with their environment are hindered.

Children with autism also face challenges with their school-based occupations (APA, 2000; Estes, Rivera, Bryan, Cali, & Dawson, 2011). Estes et. al (2011) stated that 60% of children with autism, who participated in their study, showed low achievement in at least one domain in spelling, word reading, and basic number skills despite adequate cognition. Children with autism often have difficulties in subjects that require abstract language use, reading comprehension, and problem solving (Eaves & Ho, 1997). Studies suggest that these deficits in academic achievement are correlated to their inability to express language and form friendships (Eves & Ho, 1997; Estes et al., 2001). Their struggle to communicate and establish friendships diminishes their chances to learn from people in their environment (Eaves & Ho, 1997; Estes et al., 2011). For example, when they have difficulties understanding directions from the teacher, they will not ask for help from their classmate or their teacher.

Children with autism also exhibit problems in the area of feeding (Ahearn, Castine, Nault, & Green, 2001; APA, 2000; Schreck, Williams, & Smith, 2004; Martins, Young, & Robson, 2008). They are two times more likely to have feeding problems compared to typically developing children (Martin et al., 2008). These eating difficulties may be associated with difficulties adapting to change along with oral sensory processing challenges (Martins et al., 2008). Children with autism are more likely to refuse food presented to them, to require a specific presentation of the food and utensils, and to eat only a certain type or texture of foods, such as pureed foods (Ahearn et al., 2001; Schreck et al., 2004; Martin et al., 2008). The specificity and texture of the food can limit the

options families may have to feed their child. These limitations can negatively impact the children's nutritional intake leading to malnutrition (Ahearn et al., 2001). Food selectivity and food presentation can also cause stress to families because of the time it requires to prepare the food as desired by the child (Adhern et al., 2001).

Children with autism can exhibit sleep problems. Williams, Sears, and Allard (2004), found that 53% of children with autism have trouble falling asleep, 34% of children with autism wake up in the middle of the night, 40% of children with autism are unwilling to sleep in their own bed, and 32% of parents report that they have issues waking up their child from sleep. Research shows that this population also suffers from parasomnias (sleep walking, nightmares) and sleep-disordered breathing. The reasons for these sleep difficulties remain unclear (Hoffman et al., 2004; Williams, Sears, & Allard, 2004). The disruption in sleep cycle can cause children with autism to feel lethargic during the day, thus decreasing their overall ability to pay attention in class. This may cause them to exhibit disruptive behavior that impedes their ability to learn in school (William, et al., 2004).

Children diagnosed with autism also show deficits in play. Studies show that children with autism show problems with both social and functional play (Restall & Magil-Evans, 1994; William, Reddy, & Costall, 2001). According to Williams et al. (2001), it is hard for children with autism to functionally play with their toys and elaborate on the sequence of playing with the toy. For example, children with autism can bring a toy cup to their mouth, but they will have difficulties elaborating on the function of the toy, such as sipping from the cup and smacking their lips afterwards. This is an indication that they are at a lower level of functional play than other children their age

(Williams et al., 2001). Children with autism also have trouble with social play. They often play alone with specific toys that interest them, or objects presented to them. Their ability to play is also impacted by their difficulties communicating with others, but there may be additional factors that contribute to the delays (Restall & Evans, 1994).

Challenges to Family Life

Families with a child with autism face a unique set of challenges to family life. While parents of children with autism search for the answers to questions they may have about their child's disability, they are also experiencing their own challenges. This section of the literature review will discuss five challenges faced by parents and families of children with autism: parental depression, the difficulties of maintaining a social life, the stress on the parent's marriage, issues with siblings, and financial hardships (Bradford, 2010).

Parents of children with autism are at higher risk for depression. Emerson (2003) found that 44% of parents who had children with an intellectual disability had experienced some degree of depression. In addition, there are studies that suggest that there is a higher prevalence of depression in mothers of children with autism than in mothers of typically developing children (Olsson & Hwang, 2001; Quintero & McIntyre, 2010). Parents of children with autism have difficulties participating in social activities. Social isolation, which is known to lead to depression, can be caused by missed opportunities to socialize with friends, family, and the community because of the child's behaviors (Olsson & Hwang, 2001).

Parents also are challenged by the family's loss of a social life. Parents of children with autism are less able to make changes to their daily schedule because of the

need to maintain a strict routine (Larson, 2006). Parents abstain from making changes to a schedule because of behavior problems (mainly tantrums) exhibited by the child (DeGrace, 2004; Larson, 2006). Therefore they are unable to participate in spontaneous activities outside of the home such as shopping, eating at restaurants, meeting with friends, or taking day trips with the family (Larson, 2006). These parents need to uphold the rituals and routines of a child with ASD in order to avoid inappropriate behaviors (e.g. tantrums, crying, collapsing to the floor, and hitting) (DeGrace, 2004; Hutton & Caron, 2005; Schaaf et al., 2011). Families also attempt to plan vacations around the needs of the child with autism. This can be difficult for the parents because of the limited variety of vacation areas that would cause the fewest incidences of inappropriate behaviors. Therefore families may choose not to take vacations, or may limit them to no longer than a few days (DeGrace, 2004; Hutton & Caron, 2005; Schaaf et al., 2011).

Parents of children with autism also experience additional marital stress. Parents of children with autism are 3% to 9% more likely to divorce when compared to parents of typically developing children (Hartley et al., 2010; Risdal & Singer, 2004). Although the divorce rate of parents with autism is small, the percentage still reflects a statistically significant difference in rates of divorce (Reyns, 2005). There are multiple factors that contribute to marital challenges. Parents of children with autism found it difficult to find time to get away as a couple because they were unable to find appropriate childcare (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Parents of children with autism reported that due to a lack of quality time with their spouses led to higher levels of perceived stress, which resulted in lower marital satisfaction (Higgins, Bailey, & Pearce, 2005; Reyns, 2005). Reyns (2005) found that the lower level of marital satisfaction was

the result of negative behaviors that the parents directed towards each other. For instance, parents would blame each other for the disability of their child, place misdirected anger towards one another, and found it difficult to support each other through hard times (Reyns, 2005).

Siblings are also affected by diagnosis of autism in the family. Parents of children with autism may have difficulties evenly distributing time and attention to each child in the family (Hutton & Caron, 2005). Hutton and Caron (2005) found that 75% of the siblings in their study harbored feelings of jealousy and resentment towards the child with autism because of the increased attention their sibling received. Siblings also reported feeling unfairly treated because the child with autism was held to a lower standard by the parents in regards to domestic responsibilities (Howlin, 1988; Meadan, Halle, & Ebata, 2010; Ross, & Cuskelly, 2006).

Finally, families of children with autism also face significant financial burdens. The average cost for full-time early intervention therapies for a child with autism is \$40,000 per year (Ganz, 2006). Families may be forced to pay for unreimbursed services, including medical and therapy services, prescription drugs, non-prescription drugs, and other medical services (Higgins et al, 2005; Sharpe & Baker, 2007). Some parents choose to leave their jobs because they are unable to find appropriate and cost effective child care or therapy services and behavioral services for their child, leading to loss of income. These services are fairly intensive and expensive and as a result the parents would rather stay at home in order to attend to their child's issues (Kogan et al., 2008; Sharpe & Baker, 2007).

Challenges of Underserved Families with Special Healthcare Needs

Children with autism fall under the category of children with special health care needs (CSHCN). Children with special health care needs require medical services more frequently than children without special health care needs (Kogan, Newacheck, Honberg, & Strickland, 2005). Families who are not able to obtain sufficient services for their medical needs are classified as under-served (Mundt, 1998). There are several factors that contribute to the limitations in accessing health care by underserved families with CSHCN. They include socioeconomic status (SES), insurance status, race/ethnicity, health status, and immigration status (Lykens et al., 2009; Newacheck et al, 2002; Thomas et al., 2007).

Socioeconomic status (SES) is one of the most significant factors that influence access to health care for CSHCN. Durkin et al. (2010) found that inconsistency in accessing health care attributed to low SES can cause a decrease in appropriate diagnoses and services in children with autism. Lykens et al. (2009) found that families with lower SES also tended to have lower levels of parental education. Families with less education were more likely to have unmet medical needs caused by a lack of knowledge or education (Lykens et al., 2009). Additionally, Lykens et al. (2009) found that parents with lower education had lower expectations of care. This lower expectation of health care services by the parents could greatly impact the quality of care that CSHCN receive (Lykens et al., 2009).

Park, Turnbull, and Turnbull (2002) found that financial barriers that contribute to a family's low SES status also influence their ability to access health care. Families with financial barriers were less likely to afford the needed health care services required for

their CSHCN and as a result, did not have access to the needed services (Park, Turnbull, & Turnbull, 2002). For example, families with lower SES often have decreased access to insurance. Newacheck, Mcmanus, Fox, Hung, and Holfon (2000) found that CSHCN who were insured were more likely to have a regular physician, access to usual source care (medical care, dental care, prescriptions, mental health, and eye care), and be in regular contact with their clinician/physician on an annual basis. In contrast, those CSHCN who were uninsured were considerably more likely to have unmet healthcare needs (Newacheck et al., 2000).

Honberg, McPherson, Strickland, Gage, and Newacheck (2005) found that race and ethnicity also influence access to health care. Race and ethnicity can influence health care coverage and quality of care (Blumberg et al., 2010; Coker et al. 2010; Flores & Nugi, 2006; Raphael et al., 2009). Parents of both Hispanic and African American CSHCN report less satisfying and adequate interactions with their healthcare providers when compared to Caucasian parents of CSHCN (Coker et al., 2010; Flores & Nugi, 2006). The minority parents did not feel that their providers spent adequate time with them or listened attentively to their concerns. The parents also reported that their providers were less likely to collaborate with them regarding their child's care (Coker et al., 2010). The medical providers' lack of knowledge about cultural norms can lead to culturally insensitive care which alienates the parents of these children. The culturally insensitive care by health care providers could be attributed to language barriers, a lack of cultural awareness, or a lack of insight on the behalf of the providers (Coker et al., 2010).

Language barriers can hinder a parent's ability to communicate and advocate for his/her child when attempting to receive care (Blumberg et al., 2010; Stevens & Shi,

2003; Sun, Sangweni, Butts, & Merlino, 1998). Flores, Abreu, Olivar, and Kastner (2006) found that 26% of Latino parents reported language problems as their primary barrier in receiving health care services for their child. Families reported that children who grew up in households with English as their second language received lower levels of family-centered care (Coker et al., 2010). Furthermore, there is additional preliminary research that suggests Hispanic children from primarily Spanish-speaking homes were not as likely to be recognized as CSHCN (Blumberg et al., 2010). The negative cultural perception of disabilities within Spanish-speaking families is a possible factor for the lower levels of identification of CSHCN (Blumberg et al., 2010).

Immigration status is a contributing factor to access to health care services. Berk, Schur, Chavez, and Frankel (2000) found that undocumented immigrants were less likely to navigate through and use healthcare services. Children of both documented and undocumented immigrant parents were more likely to be uninsured compared to children with citizen parents (Flores, Abreu, & Tomany-Korman, 2006; Ku & Matani, 2001). Even when services were available to citizen children with non-citizen parents, the children were less likely to receive care due to fears surrounding immigration status (Ku & Matani, 2001).

Statement of Purpose

According to the Kidsdata (2010), approximately 5.7% of Marin County's population of children has a diagnosis of autism. The Hispanic community of Marin County forms the largest minority group consisting of 15.5% of the population (U.S. Census Bureau, 2010). This was the target underserved population for this project. The purpose of this project was to create a parent resource for the Marin Autism Collaborative and education

guide regarding the signs and symptoms of autism, the process of diagnosis, and the service delivery. The resource and education guide was presented in a fotonovela format. The fotonovela is an effective tool in educating the Hispanic community in Marin County about autism. This project may potentially bridge the gap in autism awareness within this hard to reach population and underserved community by providing an education-resource guide in a culturally appropriate format. The behavioral objectives addressed were: 1) Parents targeted will be informed about how to identify the signs and symptoms of autism. 2) Parents targeted will be educated on where to initially receive services for their child in Marin County. 3) Parents targeted will be informed on the initial process of receiving services for their child in Marin County.

Theoretical Framework

The Ecology of Human Performance (EHP) framework was used as foundation to create this project. EHP looks at the interaction a person, context, and task to determine the occupational performance of the person (Dunn, Gilbert, & Parker, 1997). According to the EHP framework, the person is unique and complex (Dunn, 2007). Every person gains different experiences in his/her life and has different interests. The person also possesses unique sensorimotor, cognition, and psychosocial skills (Dunn, 2007).

The context is the person's environment. The person is embedded in the context. The context can either hinder or enhance the person's interests and abilities to perform tasks (Dunn, 2007). The environment includes temporal, physical, social and cultural aspects. The temporal environment relates to time, and includes the person's age, life-span, developmental age, and health. The physical environment includes inanimate objects such as buildings, cars, computers, etc. The social environment includes family

members, friends, and society. The cultural environment involves values, beliefs, laws, and behaviors (Dunn, Brown, & McGuigan, 1994).

The EHP framework replaces the term “occupation” with the term “task” to simplify and make the language more universal and easily understandable. Tasks are activities in which a person chooses to participate (Dunn, et al., 1994). These tasks are meaningful to the person. The tasks develop meaning through the person’s interaction with the environment and the person’s experiences (Dunn, 2007).

A variety of different tasks exist around each person (Dunn et al., 1994). Performance takes place when the person interacts with the context and participates in the tasks. EHP explains that if a person is in a context surrounded by tasks, the person will use his/her skills and abilities to perform those tasks. The performance range is affected by the interaction between the different contexts and the person (Dunn et al., 1994; Dunn, 2007). There are two ways performance range can be limited. The person can either lack the skills necessary to meet the task, or the person may have inadequate task context for a performance to occur (Dunn, 2007). A setting with inadequate task or unsupported context will not provide necessary resources for a person to perform a task at the standard of his/her skills and abilities. The performance range in this situation is determined by the context and task available for the person (Dunn et al., 1994).

EHP outlines five intervention strategies to address occupational performance challenges: establish/restore, alter, adapt and modify, prevent, and create (Dunn et al., 1994). Establish/ restore is the only strategy that focuses on changing the person. Therapists using this intervention approach focus on helping the person to establish new skills and abilities, or restore abilities that have been lost (Dunn et al., 1994).

The alter intervention focuses on changing the context. In this intervention, the occupational therapist matches an individual with the most appropriate context (Rempfer, Hildenbrand, Parker, & Brown, 2003). An entirely different context is introduced as an intervention plan, rather than changing the specific aspects in an environment.

Alternately, an occupational therapist can apply the adapt/modify intervention by adapting the task and context to expand the client performance range. This will help promote performance in the context of the client (Dunn et al., 1997).

The goal of the prevent strategy is to anticipate potential problems that could put a client in danger or could hinder performance (Dunn et al., 1997). Finally, the create intervention is defined as a method to promote more adaptable performance for the person within his/her context (Dunn et al., 1997). This intervention method does not assume that a person has a disability. The focus of this approach is enriching and adapting the context and accessible tasks in order to increase the quality of a person's performance (Dunn et. al., 1997). The create intervention focuses on the larger population. This intervention does not assume that there is a problem that needs to be fixed; rather it uses knowledge from the experts to assist the community before the problem arises.

The "create" intervention provided a basis for the development of the *fotonovela* (photo book) a resource guide for underserved families of Hispanic descent. The resource guide aimed to enrich the context of the underserved Hispanic families. It provided basic knowledge regarding the signs and symptoms of autism as well as resources that can be accessed in Marin County. In addition, the EHP model guided this project because it takes into consideration the underserved Hispanic population of Marin

County surrounding context and incorporates it into the storyline of the fotonovela. Furthermore, EHP uses language that is universal to the target population we intend to educate, the agencies involved with this project, other agencies that may be interested in utilizing this project and occupational therapists.

Methodology

Design

The purpose of this project-based thesis was to create a culturally relevant autism resource and education guide. The guide was created to educate the underserved Hispanic population in Marin County. The project used a fotonovela design that has been found to be an effective tool in distributing information within the Hispanic community (Cabreraa, Morisky, & Chin, 2002; Unger, Molina, & Baron, 2009; Valle, Yamada, & Matiella, 2006). A *fotonovela* is a Spanish language photo-book that tells a dramatic storyline (Flora, 1980).

The fotonovela format is a culturally appropriate tool because it presents the information in a medium that the Hispanic community comprehends (Carrillo & Lyson, 1983). The fotonovela design provides information utilizing photos and balloon dialogue to convey a clear and concise message. The format is ideal for underserved Hispanic individuals who that have lower levels of literacy because it is a simple and clear tool (Valle et al., 2006).

Cabreraa et al. (2002), created a fotonovela that educated Hispanics immigrants about tuberculosis. The study found that a fotonovela was a valuable tool that presented the information in a clear and culturally relevant format (Cabreraa et al., 2002). Further

studies have also revealed similar findings. Valle et al. (2006) studied the use of a fotonovela as a tool to educate older Hispanic adults about dementia. The research found that 73.1% of males and 92.9% of females found the fotonovela to be an informative tool. The researchers also reported that the fotonovela was a cost-efficient tool that was successful in educating inaccessible populations (Valle et al., 2006). Unger et al. (2009) described that a fotonovela was an effective tool in educating adults about diabetes. The participants were able to correctly answer more questions about the nature of diabetes after reading the fotonovela.

A fotonovela has been shown to be an effective tool for a variety of health conditions. Fotonovelas can similarly be effective within the autism community in Marin County. This specific fotonovela may potentially be an effective tool to communicate culturally relevant information about autism and resources available in Marin County. This design guided the project to educate the underserved and inaccessible monolingual Spanish speaking, bilingual, and bi-cultural individuals in Marin County.

Agency Description and Target Population

The Marin Autism Collaborative (MAC) was the community partner for this project. MAC is a collaboration of organizations, consumers, and family members. Partner organizations include: The Golden Gate Regional Center (GGRC), The Marin County Office of Education, Marin SELPA, Area Board 5, Matrix, Lifehouse, United Cerebral Palsy of the North Bay, Easter Seals, The Cedars, Opportunity for Independence, non-public private schools, and residential and adult day centers and consultants (Marin Autism Collaborative, 2011). MAC focuses on the needs of

individuals and families with autism in Marin County. MAC meets monthly to identify missing services and work toward finding solutions for the services that are not being provided to individuals and families with autism (Marin Autism Collaborative, 2011).

(Appendix A)

The largest minority group in Marin County is the Hispanic population at 15.5% (U.S. Census Bureau, 2011). Based on this percentage, it was determined that the target population of this project would be the underserved Hispanic families who have a children with autism living in Marin County.

Ethical Concerns and Considerations

The Occupational Therapy Code of Ethics and Ethics Standards guided this project thesis. Five of these ethical principles were addressed throughout this project thesis: social justice, veracity, autonomy and confidentiality, and fidelity.

Social justice is the responsibility to inform society about occupational therapy services that promote health and wellness to reduce impact of disease and disability (AOTA, 2010). The occupational therapy profession has an obligation to prevent social inequality. Occupational therapists believe that they need to advocate for just and fair treatment for all patients and clients, specifically when it relates to health care services (AOTA, 2010). The creation of the fotonovela provided information and resources about autism to a previously inaccessible, underserved Hispanic community in Marin County.

Veracity is defined as being accurate and honest when disseminating information (AOTA, 2010). A comprehensive and accurate account of the purposes of the project thesis was related to the participants. The principle of veracity was implemented by having the participants made aware of their role and expectations in this project thesis

prior to their participation. The flyers and materials used for recruitment of participants were also accurate and honest in describing the project and the role of the participant. Both the flyers and materials used for recruitment of participants were provided in English and Spanish to assure the accuracy of information provided (AOTA, 2010) (Appendix B).

Autonomy and confidentiality are principles ensuring an individual's right to privacy and self-determination (AOTA, 2010). These principles were considered and addressed during the creation and implementation of this project thesis. The participants who were interviewed were provided with audio consent forms (Appendix C). This ensured that the participants were aware that their stories were going to be used for the purposes of this project thesis. The non-professional actors who agreed to participate in the photo shoot were provided a photo consent form (Appendix D). All participants were informed of the purpose of their involvement in the project and were given the right to discontinue their participation at any time. To ensure confidentiality, the participants' information was only available the creators of this project thesis and their thesis advisor. To further ensure the participants' privacy, their contact information was placed in a secure file on a password secured computer located in one of the project creator's home offices. All identifying information was removed in the creation of this project thesis.

The principle of fidelity also was addressed and considered during interactions with other professionals and agencies (professional photographer, story board consultant, MAC, and Matrix) in the creation of this project (AOTA, 2010). The principle of fidelity is defined as the fair and respectful treatment of other professionals. Individuals from other professions and agencies that collaborated in the creation of the fotonovela were

treated with integrity, respect, and fairness. These individuals were acknowledged for their parts in the project. A computer program called “Comic Life 2” was used in the creation of the fotonovela. The program was purchased and usage agreements were adhered to.

Project Development

Several steps were taken to produce the final fotonovela product. Originally, the first phase was to run a focus group exploring the hurdles and barriers Hispanic families encountered during their attempts to receive services for their child. Due to difficulties in recruiting members to participate in a focus group, we needed to reevaluate how the stories were going to be obtained.

We contacted different agencies (MAC, GGRC, San Rafael School District, and Marin Head Start Program) to assist the project in finding eligible candidates that fit the criteria. The two recruitment criteria that were requested from the different agencies was the participants were Hispanic and they were Marin County residents. Due to HIPAA regulations these agencies were not allowed to disclose the names and phone numbers of their clients and possible potential participants. In order to abide by HIPAA regulations an informational flyer, in English and Spanish, explaining the purpose of the project was created and given to the different agencies to help recruit participants (Appendix B). The flyer was then distributed by the agencies to their known potential candidates. A phone number was placed at the bottom of the flyer in order for potential candidates to have the option to call and offer to share their stories. Despite these attempts, no participants responded to the flyers that were distributed.

Rocio Smith, the Executive Director at Area Board 5 on Developmental

Disabilities was able to direct us to four Hispanic families of children with autism living in Marin County and Contra Costa County. Contact information was exchanged between a member of the thesis group and the families, and a meeting time was set up. The parents were asked to tell their stories about their child and their process of receiving an autism diagnosis. These parents were asked when they realized that their child was not behaving like other children similar in age. In addition, the parents shared steps that they took to get their child diagnosed, who they spoke to after their child's diagnosis, and which services were the most helpful. The interviews were conducted in Spanish. The interviewed parents signed an audio consent form to allow the information taken from their interviews to be used in the fotonovela (Appendix C).

In the end, four narratives were volunteered, recorded, and transcribed in Spanish. A group member of the thesis project translated the stories from Spanish to English with outside resources and support.

A master script was created in English using the four transcribed stories by selecting important information and common recurring themes from each of the stories (Appendix E). Some of these themes were: denial of the father, the mother taking a large role in seeking out for appropriate services, and the concern about the cost of the services being provided. Highlighting those themes was an important step in the creation of the script.

After finalization of the script, a meeting was scheduled with Assistant Professor John Duvall from the Communications and Media Department at Dominican University to discuss the creation of a storyboard. After the meeting, a hand-drawn storyboard of the script was generated. The storyboard created the story outline for the fotonovela and

particular photo shots that were going to be needed to create the scenes (Appendix F).

Models were recruited for the pictures in the fotonovela. A professional photographer volunteered his services prior to the recruitment of the models. The roles needed for the fotonovela were friends, family members, a child, a doctor, a social worker, and a psychologist. The models included occupational therapy students, family members, and friends. The recruited models posed in photos that matched the different scenarios that were created from the storyboard. The recruited models signed a photo consent form to allow their photos to be used in the fotonovela (Appendix D).

Project Implementation Plan

Creating the fotonovela required purchasing, uploading, and arranging the photos into a computer program called “Comic Life 2.” The story was conveyed from page to page through balloon dialogue using the English version of the master script. The thesis advisor of this project and MAC formed a list of useful autism resources in Marin County to help the reader gain initial access to appropriate services. An “Additional Information” page was also created to help the reader understand some of the details of the initial steps to take if their child is under or over the age of three. These two pages were included in the fotonovela.

A rough draft of the fotonovela in English was sent to MAC for feedback and approval. After the English version of the fotonovela was granted approval, the fotonovela was translated into Spanish by a group member of the thesis project with support from outside sources. The finished English and Spanish versions of the fotonovela were digitally sent to MAC for distribution (Appendix G).

Currently, the plan for distribution of the fotonovela is being decided by MAC.

Project Evaluation Plan

An evaluation of the effectiveness of the fotonovela was conducted using a Likert scale created online through a website called SurveyMonkey[®]. A Spanish version of the Likert scale was created and emailed to the families that offered their narratives after they read the story (Appendix H). An English version of the Likert scale was created and given to practicing occupational therapists and professionals who have been guiding this thesis group to create the fotonovela (Appendix H). The survey was sent to 11 people, and of the 11 surveys, seven people responded. The Likert scale was a five-level scale starting from, “5: Strongly agree” to “1: Strongly disagree.” The participants were asked to give an anonymous, objective opinion of the information that was conveyed through the fotonovela. The questions asked on the Likert scale pertained to how informed and educated the participants felt after reading the fotonovela. The effectiveness of the fotonovela was determined, based on the scores obtained from the Likert scales.

Question	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)	Average
1. The story was easy to understand.	0	0	0	2	5	4.71
2. The information about autism was helpful	0	0	0	2	5	4.71
3. The format of the fotonovela was culturally relevant.	0	0	1	1	5	4.57
4. Based on the information on the resource page I would know who to call for information.	0	1	0	3	3	4.14
5. I would recommend this fotonovela to other families of children with autism.	0	0	1	2	4	4.43
6. The fotonovela was visually appealing.	0	0	0	2	5	4.71

After sending out the survey to therapists and professionals, we realized that we had not clarified the target population for the fotonovela. Some of the responses reflected a misunderstanding of the purpose of the project related to the target population. Some responses were: “would like more generic resource information that all families can use”, “It is limited to Marin county and I live in Contra Costa” and, “Would recommend a more geenric [sic] version so that it can be used statewide. It would be a shame if other paretns [sic] cannot take advantage of such a great resource.” It was clear that an explanation was needed in order for the participants to understand that the purpose of the fotonovela was designed specifically for underserved Hispanic families in Marin County.

Aside from the misunderstanding, the fotonovela was given high praise from the survey participants. Some examples of responses were:

- “I think that it is wonderful a culturally specific tool has been created. Perhaps there are other tools for other cultures that can be developed as well. A next step would be to share it with Autism Speaks and for it to be added to their free kit downloads.”
- “The fotonovela kept my attention. It was professionally done and provided enough information to guide a person on what they should do without overwhelming them with too much medical/educational information.”

Discussion, Summary, and Recommendations

The number of children receiving a diagnosis of diagnosed with autism is increasing (Kidsdata.org, 2010). Autism is a disorder that affects all racial, ethnic, and socioeconomic backgrounds (CDC, 2012). There are communities and families that are unable to access the medical services necessary for their children. These communities

and families exist in Marin County and they are considered to be underserved. Therefore, the focus of this project-based is on the underserved Hispanic community, the largest minority group in Marin County (U.S. Census Bureau, 2011).

After a discussion with MAC it was determined that an informative resource guide was needed for the Hispanic community. The purpose of this project was to create a culturally relevant autism resource and education guide specifically for the underserved Hispanic community in Marin County. A fotonovela design was chosen because there is strong research evidence that it can be a culturally appropriate communication tool to convey information to the Hispanic community (Carrillo & Lyson, 1983). The fotonovela script was created from data gathered from interviews of Hispanic parents of children with autism. Once the script was formed a story board was created and models were recruited for the pictures in the fotonovela. A computer program called “Comic Life 2” was purchased, used to arrange the photos, and create the fotonovela. Both an English and Spanish version of the fotonovela were created.

Once the fotonovela was completed, copies were sent out to the families whose narratives were used for the script, practicing occupational therapists, and other professionals for their feedback on the fotonovela. The majority of the feedback given was positive and enthusiastic. All the reviewers felt that the fotonovela would be an effective tool to present information and resources to the Hispanic community.

Limitations

For the most part, the project implementation went as planned. However, there were a number of limitations to the fotonovela project. The first challenge we experienced was the limited volunteered participants from Marin County. The initial

recruitment for narratives was done in Marin County alone. Due to the minimal number of individuals in Marin County who were willing to share their stories, the scope of recruitment expanded to any Hispanic families of children with autism. Additional families were then recruited from Contra Costa County. It was discovered that immigration status interfered with recruitment in Marin County. Participants refused to give their stories for fear of deportation. This factor caused the anticipated completion time to be extended, because of the limited volunteered stories. However, with some patience and expanding the recruitment criteria, four participants volunteered to share their stories to help generate the general story for the fotonovela.

Another limitation discovered was the resources provided in the fotonovela were limited to Marin County. The fotonovela storyline and service delivery were specific to individuals living in Marin County. Therefore, some of the specifics of the story may not be as applicable to individuals living outside of Marin County.

A third limitation discovered was the ability to convey the information to individuals who are illiterate may not be able to utilize this fotonovela. Currently, the fotonovela is not offered in an auditory format.

A fourth limitation was the storyline of the fotonovela. This was limiting because of the four stories were gathered to create a comprehensive story this may not represent the Hispanic population of Marin County as a whole. There exists the possibility that the story may be missing important events that the Hispanic population may encounter when trying to access services for their child in Marin County.

The last limitation identified was that the storyline of the fotonovela portrays the process of accessing services for children who are under the age of three. The story did

not describe the process for accessing services through the school district for children over the age of three. Therefore the fotonovela is most relevant and useful only to parents who have children under three years old.

Overall, we felt that the thesis process was challenging but rewarding. One important aspect that we learned from creating this fotonovela was how difficult it was finding participants to offer their experiences in obtaining services. Even though we originally faced that challenge of not obtaining enough participants, we were fortunate to be able to expand our recruitment pool to Contra Costa County, with the help of Rocio Smith.

We also had that opportunity to engage and be exposed to the Hispanic community. This was a great opportunity to provide culturally sensitive resource to a population who is underserved. From this population, we also learned that the mother plays a big role in a child's life. Often times, it is the mother who initially notices that their child is not meeting developmental milestones. Therefore, it is the mother who initially seeks help from professionals to help their child receive services they may need.

We were also encouraged by the positive feedback that we received from the many professionals and parent participants who have read and reviewed our fotonovela. They felt that it has a potential to be a great education and resource guide to help the underserved Hispanic population gain access to initial services for their child. It is rewarding to know that our project will be an effective tool in presenting information and resources to the Hispanic community. Our hope is that this will become a resource that can be universally modified and utilized throughout the state of California.

Recommendations

A recommendation for future projects would be to develop an audio and/or a web-based format of the fotonovela to allow individuals to access this education and resource guide. In addition, another fotonovela should be developed to portray the story of a child who is three years of age or older to help guide the parents to access initial services for their child. An additional recommendation would be to create a fotonovela that can be generalized enough to be used statewide. Further research is also needed to determine the effectiveness of the fotonovela design in communicating information regarding autism in the Hispanic community.

Occupational Therapy Implications

While fotonovelas are increasingly used to provide information on a wide variety of healthcare topics, a search of the literature found no examples of a fotonovela on issues related to autism. According to AOTA (2008), an occupational therapist's role is to promote health and participation in individuals, different groups of people and populations, and to enhance occupational performance. One of the occupational therapy implications of this project is the need to provide services to the growing population of Hispanic families in the United States (U.S. Census Bureau, 2011). With autism diagnoses on the rise in California (Kidsdata.org, 2010), there is a greater need for families to be better informed of available services. This fotonovela specifically acts as a health care education tool describing the signs and symptoms of autism, and the process for receiving services for the underserved Hispanic population living in Marin County.

By providing information about autism and services, in a culturally-relevant format, to the underserved Hispanic population in Marin County, occupational therapists

are advocating for this growing population, and thus advocating and promoting the field of occupational therapy as a whole.

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Appendices

APPENDIX A

**Dominican University of California
Department of Occupational Therapy
OT 5110: Thesis Proposal: Site Selection Verification Form**

<p>Student Name:</p>
<p>Title of thesis project or research:</p>
<p>Description of thesis project or research:</p>
<p>Name of Proposed Site:</p>
<p>Person with whom you will be working:</p>
<p>Type of facility:</p>
<p>Address:</p>
<p>Phone #:</p>
<p>Contact Person related to approval at the site:</p>
<p>Title:</p>
<p>Has initial contact been made? Yes No</p>
<p>If "yes", describe:</p>
<p>If "no", state <u>specifically</u> when contact will be made (a site approval is necessary for the thesis proposal to receive approval):</p>
<p>What agreements have been made regarding project implementation (for example, collect data, prepare a manual, or develop an intervention)?</p>
<p>Dates for proposed intervention(s), due date for manual, or dates planned for data collection:</p>
<p>Potential problems, plans for addressing problems (pro-active planning for alternatives)</p>
<p>Agency Signature _____ Date _____</p>
<p>Print Name & Title of Agency person _____</p>
<p>Faculty advisor signature:</p>

LOS PADRES DE NIÑOS CON AUTISMO



La meta de este proyecto es brindar información y recursos a la comunidad bajo representada de familias hispanas sobre el autismo (e.g. cuales son los síntomas?, donde se puede diagnosticar?, como conseguir ayuda?) usando el formato de un libro fotografico que describe una historia dramatizada (una fotonovela). Nuestro deseo es que este proyecto actúe como una guía para las familias afectadas de como entender los síntomas del autismo y como obtener servicios. Solicitamos familias afectadas que pudieran compartir su historia con nosotros. Su privacidad sería completamente protegida y cualquier información brindada sería protegida bajo la más estricta confidencialidad.

Si quisiera más información sobre como participar en este proyecto, por favor contacte al grupo de Terapia Ocupacional al: [510.427.6604](tel:510.427.6604)



PARENTS OF CHILDREN WITH AUTISM



1. The purpose of our project is to better inform underserved Hispanic families with information on autism (i.e. signs and symptoms) and resources (i.e. where to get diagnosed, support services, educational services) in the form of a dramatic storyline in a photo book (fotonovela).
2. This project will hopefully act as a guide for families to understand the signs and symptoms of autism and the process of receiving services.
3. We are seeking families who are willing to share their stories with us. All shared stories remain completely confidential.
4. If you would like more information on how to participate in this project, please contact the Department of Occupational Therapy: (510) 427.6604



APPENDIX C

Dominican University of California
Department of Occupational Therapy
50 Acacia Avenue
San Rafael, CA, 94901

CONSENT FOR AUDIO USAGE

I understand that Dominican University of California makes extensive use of audio in its advertising, publications, and other promotional materials. I further understand that the above listed materials will be viewed by the general public. I have been advised that I have the right to refuse to participate in audio. I hereby consent to participate in and authorize the use of my audio by Dominican University of California for its advertising, publications, and other promotional materials.

Date: _____

Name:

Signature:

APPENDIX D**Photography Consent Form**

I hereby grant full permission to Dominican University of California, Occupational Therapy Department, to use either my photograph and name (if necessary) or my child's photograph and name (if necessary) in any publication or advertising materials (printed or electronic). This consent also serves to waive all rights of privacy or compensation that I may have in connection with the use of my photograph and/or name or my child's photograph and/or name.

Name

Relationship To Child (if applicable)

Child's Name (if applicable)

Address:

City:

State:

Zip:

Signature:

Phone Number

APPENDIX E

Title page

Pablo's Story: Learning about Autism

La Historia de Pablo: Aprendiendo sobre el Autismo

By: Tiffany Chi, Monica Guzman, & Isaac Stahlhut

Autores: Tiffany Chi, Monica Guzman, & Isaac Stahlhut

The word "Copyright" on the copyright page

ÓCopyrighted by Marin Autism Collaborative

Derechos de Autor Ó Marin Autism Collaborative

The words "Meet the characters"

“Los Personajes”

Ana Garcia

Felipe Garcia

Pablo Garcia

Maria

Dr. Louis

Social Worker Heather trabajadora social Heather

Brittany

Psychologist David Psicólogo David

Autism Fotonovela Script

Scene 1:

- Birthday party at the park: Pablo sitting on the ground while the other children are playing together.

Fiesta en el parque: Pablo está sentado en el piso mientras que otros niños están jugando juntos.

Box 1:

(Description above)

Box 2: (Brittany talking to Pablo, Ana and Maria standing and talking to each other next to Brittany and Pablo.)

Brittany: What is wrong Pablo? Don't you want to play with the others?

¿Que pasa Pablo? ¿ No quieres jugar con los otros niños?

Ana: Oh, he likes to play by himself. He entertains himself well.

Oh, a él le gusta jugar solo. Se entretiene bien.

Box 3:

Maria: Does he play by himself a lot?

¿ Juega solo mucho?

Ana: Yeah... he does. Is that something I should worry about?

Si. ¿Es algo que me debe de preocupar?

(Note: This triggers Ana to worry about Pablo)

Box 4:

(Pablo playing on the ground with Ana looking on.) (Photo shot over her shoulder with a view of Pablo lining up toy cars.)

Ana: Is there something wrong with my Pablito?

¿Le pasa algo a mi Pablito?

Scene 2: Living room

- Felipe (father) is sitting on the couch reading the newspaper. Ana (mother) is sitting on the floor of their living room with Pablo

- Pablo is around 23 months old

Box 5:

Ana: Hi Pablito! Look at me!

¡Hola Pablito! ¡Mirame!

(Pablo is not looking at mom. He is staring at his hands while playing with his fingers)

Living Room of the Garcia's home.

Sala de la casa de los Garcia.

Box 6:

Ana: How come Pablo isn't looking at me? Is there something wrong with him?

¿Porque no me está mirando Pablo? ¿Le pasa algo?

Felipe: He is busy looking at his hands. Let him play. There's nothing wrong with him.

Está ocupado mirando a sus manos. Hay que jugar con él. No le pasa nada.

Box 7:

Ana: I don't know, Rosa (daughter) always loved playing with me at her age.

No sé, a Rosa (hija) siempre le encantaba jugar conmigo a esa edad.

Felipe: He's a boy, and I used to do the same thing.

El es un hombrecito, y yo era igual.

Box 8:

Ana: The ladies at the birthday party yesterday said that he should be playing with other children. Maybe I'll mention it to the doctor the next time I take Pablo for a check-up.

Las mamás en el cumpleaños de ayer dijeron que el debería estar jugando con los otros niños. A lo mejor se lo menciono al doctor la próxima vez que lleve a Pablo para su cita.

Felipe: There is nothing wrong with our Pablito. He was just like me when I was a kid.

No le pasa nada a nuestro Pablito. El es igualito como yo era de niño.

Box 9:

(Ana walks away with Pablo while Felipe keeps reading the newspaper.)

Scene 3: Dr. Louis' office

- (One month later)

-(Un mes después)

- Ana and Dr. Louis are standing in the doctor's office.
- Pablo is sitting on the doctor's bed.

Box 10:

Dr. Louis: Hello Ana, Hi Pablo! Wow! He is two years old already!

¡Hola Ana, Hola Pablo! ¡Wow! ¡Ya tiene dos años!

Ana: Yeah, he's such a big boy, but I'm still worried about him. I know we talked about this before, but he still does these things:

Si, ya esta grandecito, pero todavía me preocupo por él. Sé que hemos hablado de esto antes, pero todavía noto que él:

- He doesn't talk
- No habla
- He doesn't look at me
- No me mira
- He has trouble sleeping
- Tinene dificultad durmiendo
- He doesn't play with other kids
- No juega con otros niños
- He walks on his tip-toes
- Camina de puntitas
- He plays with his hands
- Juega con sus manos
- He has problems with loud noises
- Tiene problemas con ruidos altos

Box 11:

Dr. Louis: Okay. Let's see what's going on. Did you fill out developmental checklist while you were waiting?

Okay. Hay que ver que puede estar pasando. ¿Llenaste la lista de verificación del desarrollo mientras que estabas esperando?

Ana: Yes. Here it is.

Si, aquí está.

Box 12:

"Checklist"

Lista de Verificación

Does your child use two-word sentences by age 2?

¿Su hijo usa frases de dos palabras a los 2 años?

Does your child imitate actions or words?

¿Su hijo imita acciones o palabras?

Does your child pretend play?

¿Su hijo usa su imaginación para jugar?

Does your child walk only on their toes?

¿Su hijo camina solo de puntitas?

Does your child follow simple instructions by age 2?

¿A los 2 años, su hijo puede seguir instrucciones simples?

Can your child push a wheeled toy by age 2?

¿Su hijo puede empujar un juguete con ruedas a los 2 años?

Did your child experiences a dramatic loss of language or social skills they once had?

¿NotóHa notado una reducción dramática en el lenguaje o la capacidad social de su hijo?

Does your child point or bring objects to you?

¿Su hijo señala o te trae objetos?

Does your child respond to his/her name ?

¿Su hijo responde a su nombre?

Note: This will be a checklist for the readers to answer about their own child.

Box 13: (20 Minutes later)

(20 minutos despues)

Dr. Louis: Based on your answers and my observations I have some concerns about Pablo's development. I recommend that you contact Golden Gate Regional Center (GGRC). They are a private non-profit corporation that works with individuals with developmental disabilities. They will be able to complete a better assessment of Pablo.

Basado en sus respuestas y mis observaciones, tengo algunas preocupaciones sobre el desarrollo de Pablo. Recomiendo que te pongas en contacto con Golden Gate Regional Center (GGRC). Ellos son una corporación privada, no-lucrativa que trabaja con individuos con discapacidades del desarrollo. También podrán evaluar a Pablo con mas detalle

más a fondo

Ana: This sounds very serious. I don't think my son is disabled. Felipe said he was just like Pablo at his age.

Esto parece algo serio. Yo no pienso que mi hijo es discapacitado. Felipe dice que él era igual que Pablo a esa edad.

Box 14:

Dr. Louis: I completely understand your concern, but to be safe I would still recommend you contact GGRC. Would you like me to call them for you?

Entiendo completamente su preocupación, pero para estar seguros de todos modos recomendaría que contactes el GGRC. ¿Quisiera que los llame por usted?

Ana: I don't think this will be necessary. Thank you again Dr. Louis.

No pienso que es necesario. Y de nuevo, gracias Dr. Louis.

Scene 4: Living room couch

- Ana and Felipe are sitting on the couch talking.

- Pablo is sitting on the floor in front lining up cars on the floor.

Box 15:

Ana: We had Pablo's 2 year check up today. He told me that I should contact someplace that helps children with disabilities.

Hoy día tuvimos el chequeo de 2 años para Pablo. El doctor me dijo que debo de contactar un sitio que ayudan niños con discapacidades.

Felipe: Disability?! No, way! There is nothing wrong with him!

¡¿Discapacidad?! ¡No es posible! ¡No pasa nada con él!

Box 16:

Ana: Calm down! I don't think he is disabled either. But don't you think he should be talking? Maria's son is younger than Pablo and he is talking.

¡Cálmate! Yo tampoco creo que sea discapacitado. Pero ¿no piensas que debía hablar ya? El hijo de María es más joven que Pablo y él está hablando

Felipe: He'll talk when he has something to say. I'm going to sleep. I don't want to think about this anymore.

Hablará cuando tenga algo que decir. Me voy a dormir. Ya no quiero pensar más sobre esto.

Scene 5: Supermarket

- Ana is shopping
- Pablo sitting in shopping cart

Box 17:

(Description above; in the aisles of the supermarket) (One day at the supermarket...)

(Un día en el supermercado...)

Box 18:

(Cans fall off shelf)

Box 19:

(Pablo covering ears with his hands and screaming)

Box 20:

(Ana picks up Pablo and leaves shopping cart in the aisle)

Scene 6: GGRC Intake

Admisiones de GGRC

- Ana on the phone in the kitchen

Box 21:

GGRC: Golden Gate Regional Center intake unit, how may I help you?

Golden Gate Regional Center Unidad de Admisión, ¿Como le puedo asistir?

Ana: My name is Ana Garcia and my child does not act like my daughter and other children. Who do I speak to to find out why my child is not like other children his age?

Mi nombre es Ana Garcia y mi hijo no actúa como mi hija y otros niños. ¿Con quién puedo hablar para averiguar por qué mi hijo no es como otros niños de su misma edad?

Box 22:

GGRC: I will need you to answer some questions regarding your child's behavior in order

to determine if an assessment is necessary.

Necesito que conteste unas preguntas acerca del comportamiento de su hijo para que podamos determinar si una evaluación es necesaria.

Ana: Okay

Okay

Box 23: (5 minutes later)

(5 minutos después)

GGRC: Based on your observations of your child, I will assign an Assessment Social Worker to schedule an appointment with you within 15 days. We will send you some papers to fill out and conduct an assessment.

Basado en sus observaciones de su hijo, le asignaremos una Trabajadora Social que hará una cita con usted dentro de los próximos 15 días. Le mandaremos unos papelesformas para que las llene y haremos llenar y haremos una evaluación a su hijo.

Ana: Thank you, but I want to make sure that this will be free because I do not have a lot of money.

Gracias, pero quiero asegurarme que esto será gratis porque no tengo mucho dinero.

Box 24:

GGRC: Absolutely, Mrs. Garcia, this is a free service.

Absolutamente, Sra. Garcia, este es un servicio gratis.

Ana: Thank you and I look forward to hearing from the Assessment Social Worker.

Gracias y espero la llamada de la trabajadora social.

Scene 7: (Within 15 days) Living room of the Garcia's household

(Dentro de 15 días) Sala de la casa de los Garcia

- Social Worker Heather and Ana are talking to each other in the living room

Box 25:

Social Worker Heather: Hello, my name is Heather. I am a social worker and I will be talking to you and observing your child today.

Hola, mi nombre es Heather. Yo soy una trabajadora social y hoy estaré hablando con usted y a observando su hijo.

Ana: How long will this take?

¿Cuanto tiempo durará?

Box 26:

Social Worker Heather: About 45 minutes to an hour.

Más o menos de 45 minutos a una hora.

Ana: Okay. Sounds good.

Okay, está bien.

Box 27:

-Ana is sitting in the room with Pablo.

Box 28: (45 minutes later)

Ana: Do you think there is anything wrong with Pablo?

¿Piensas que algo pasa con Pablo?

Social Worker Heather: Based on my observation I do have concerns in about to Pablo's development.

Basada en mi observación, si tengo preocupaciones acerca del desarrollo de Pablo.

Box 29:

Ana: What do you think is wrong with him? Is he going to be okay?

¿Que piensas que le pasa? ¿Va a estar bien?

Social Worker Heather: I'm not sure exactly, but I agree with you that he should be talking and playing at this age. I am going to schedule a full assessment to be completed on Pablo by a child psychologist and GGRC is going to assign you a case manager. This case manager will set up a individual family service plan (IFSP). This will detail the goals that you have for Pablo and your family. This plan will be completed within 40 days of your first phone call to GGRC.

No estoy segura exactamente, pero estoy de acuerdo que él debería estar hablando y jugando a esta edad. Le voy hacer una cita para una evaluación completa para Pablo con un psicólogo de niños y GGRC le asignará un trabajador social. Este trabajador social coordinará un plan de servicios individualizados para la familia (IFSP). Este IFSP tendrá las metas para Pablo y su familia en detalle. Este plan será completado dentro 40 días desde su primera llamada a GGRC.

Box 30:

Ana: Thank you so much and will this be free also?

Mil gracias. ¿Esto será gratis también?

Social Worker: You're welcome, yes, all these services are free of charge.

De nada. Si todos los servicios son gratis.

Scene 8: Dining room table- (In the Garcia's Dining Room)

(En el comedor de los Garcia)

- Ana and Felipe are sitting at the dining room table talking.

Box 31:

Ana: I wanted to tell you that I had someone do some tests on Pablito to see why he doesn't look at us.

Queria, decirte que lleve a Pablito a que le hicieran unas evaluaciones para entender porqué es que no nos mira. lleve a Pablito a hacerse

Felipe: I thought we agreed that he is fine!

¿Pensé que estábamos de acuerdo que él está bien!

Box 32:

Ana: I am just worried because of what happened at the supermarket!

¡Solo estoy preocupada sobre lo que pasó en el supermercado!

Felipe: Do what you want! I still don't believe there is something wrong with him. This conversation is over!

¡Haz lo que quieras! Todavía no creo que él tenga algo mal. ¡Esta conversación ha terminado!

Box 33:

(Felipe leaves the room angry while Ana is sitting stunned by his response.)

Scene 9: Psychologist office (Within 45 days of initial contact)

Oficina del Psicólogo (Dentro de los 45 días del contacto inicial)

- Ana and Psychologist speaking in the psychologist's office.

Box 34:

Ana: Hello my name is Ana, and this is my son Pablo.

Hola, mi nombre es Ana y mi hijo es Pablo.

Psychologist: Social Worker Heather told me all about him. Thank you for bringing him in - Today I will be determining his eligibility for services through GGRC.

La trabajadora social Heather me contó sobre él. Gracias por traerlo. Hoy voy a determinar si califica para servicios del GGRC.

Box 35:

(Psychologist working with Pablo with Ana in the room sitting there)

Scene 10: (6 months later at a support group for mothers of children with autism)

(6 meses después en un grupo de apoyo para madres de hijos con autismo)

- Ana standing in front of a mock group of people

Box 36:

Ana: My son was diagnosed with autism 6 months ago through GGRC. He now sees an occupational therapist, an applied behavior analysis (ABA) therapist, and a speech therapist. Because of these services provided by GGRC, I see improvements in Pablo everyday.

Mi hijo fue diagnosticado con autismo hace 6 meses por el GGRC. Ahora el vé a un terapeuta ocupacional, un terapeuta de comportamiento, y un terapeuta del habla. Gracias a

esos servicios que ofrece el GGRC, yo veo que Pablo está mejorando cada día.

Additional information page

Additional Information

Para más información

If your child is under age 3...

Si su hijo es menor de 3 años...

An Assessment Social Worker will be assigned to you and will schedule the first appointment within 15 working days after initially contacting Golden Gate Regional Center for services. The appointment will be held at your home or at the regional center. At this appointment, your family will be given information about the regional center and about their services.

Se le asignará una trabajadora social para la evaluación y se le dará cita dentro de los 15 días hábiles después de su primer contacto con Golden Gate Regional center para solicitar servicios. La cita puede ser en su casa o en el centro regional. En esta cita le darán información sobre el centro regional y sus servicios.

If your child is between ages 0-3, assessments for eligibility of services are performed within 45 days following the first appointment. In addition, a plan called Individual Family Service Plan (IFSP) is completed within 45 days of the family's first contact with the regional center.

Si su hijo tiene entre 0 y 3 años, la evaluación para elegibilidad para servicios se hará dentro de los 45 días después de la primera cita. Además, dentro de los 45 días después del primer contacto con el centro regional, se completará para usted un plan llamado: Plan Familiar Individualizado de Servicios (IFSP por sus siglas en inglés).

3. The IFSP helps show you how goals for your child will be met as preferred by you and your family.

El IFSP demostrará cómo se cumplirán las metas para su hijo de acuerdo a sus preferencias

If your child is age 3 or above...

Si su hijo tiene más de 3 años

Immediately enroll your child into the local school or county office of education as soon as possible.

Inscríbalo en la escuela local o la oficina de educación del condado lo más pronto posible

Inform the local school or county office of education that your child has special needs and are requesting assessment and placement appropriate for your child.

Informe a su escuela o la oficina de educación del condado que su hijo tiene necesidades especiales y está pidiendo una evaluación y programa apropiado para su hijo

Bring any written request for assessments and placement during the process of enrolling your child into the new school.

Traiga cualquier documento por escrito que tenga respecto a evaluaciones o programas durante el proceso de inscripción de su hijo

Assessments will help develop an Individualized education plan (IEP) for the child.

Las evaluaciones ayudarán a desarrollar un plan individualizado de educación (IEP) para el niño

5. The IEP helps show how your child goals will be met as preferred by you and your child.

El IEP demostrará cómo se cumplirán las metas para su hijo de acuerdo con sus preferencias y las de su hijo

Resource page

Página de Recursos

1. Golden Gate Regional Center

5725 Paradise Drive, Bldg. A, Ste. 100
Corte Madera, CA 94925
(415) 945-1600
Fax: (415) 945-1630

2. Matrix Parent Network and Resources

94 Galli Drive, Ste. C
Novato, CA 94949
415.884.3535 tel
800.578.2592 toll free
415.884.3555 fax

--Matrix Parent Network and Resources provides parent education on resources and services available for child with special needs.

Matrix Parent Network and Resources ofrece educación sobre recursos y servicios que existen para su niño con necesidades especiales

3. Marin Special Education Local Plan Area - Marin County Office of Education

1111 Las Gallinas Ave.
P.O. Box 4925
San Rafael, CA 94913
(415) 499.5850

-- The Marin SELPA will provide free, appropriate public education to students with disabilities in the least restrictive environment.

El SELPA de Marin ofrece educación pública apropiada y gratis para estudiantes con discapacidades en el ambiente menos restrictivo

4. Child Development Center at California Pacific

Centro de Desarrollo Infantil en California Pacific

Sutter Terra Linda Heath Plaza
4000 Civic Center Dr., #210
San Rafael, CA 94903
(415) 492-4870

-- The Kalmanovitz Child Development Center offers a comprehensive assessment and treatment program for infants, preschoolers, school-age children and adolescents.

El Centro de Desarrollo Infantil Kalmanovitz ofrece un programa completo de evaluación y tratamiento para bebés, niños y adolescentes.
5. University of California, San Francisco, Autism and Neurodevelopment Center

Centro de Autismo y Desarrollo Neurológico , University of California, San Francisco

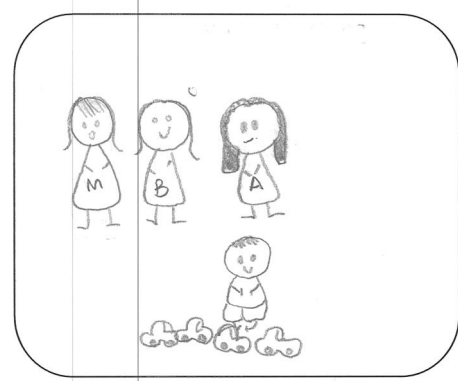
401 Parnassus Avenue
San Francisco, CA 94143-0984
(415) 476-7500

-- Services include: Clinical Assessment, Genetic Evaluation, Neurological Evaluation and Treatment

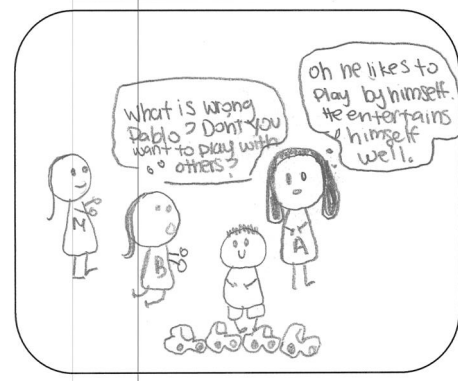
Los servicios incluyen evaluación clínica, evaluación genética, evaluación neurológica y tratamiento.

APPENDIX F

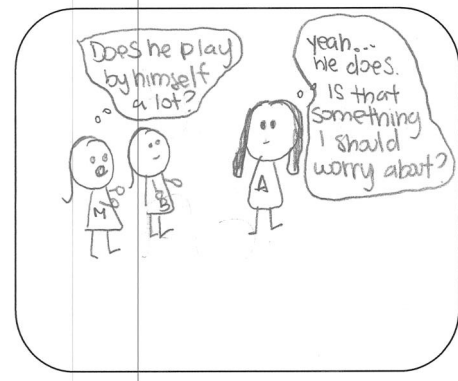
Scene 1 • B-day party in neighbor's back yard
• Pablo sitting on the ground while other children play together



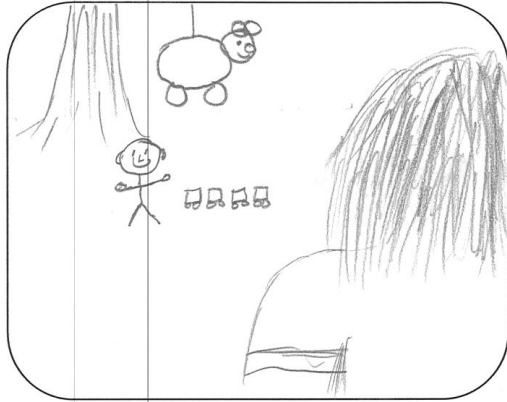
Scene: Box 1



Scene: Box 2



Scene: Box 3

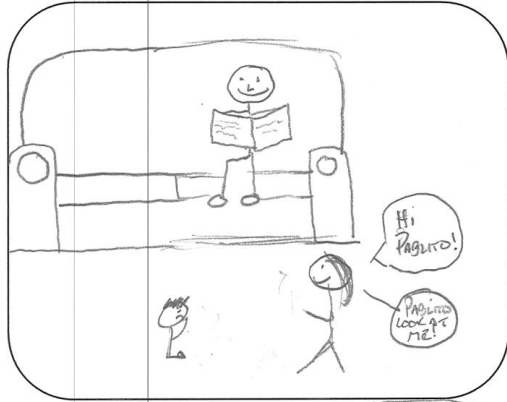


Scene: 1 4

PABLO PLAYING ON THE GROUND WITH ANA LOOKING

→ PHOTO SHOT OVER HER SHOULDER WITH A VIEW OF PABLO LINING UP TO HIS CARS.

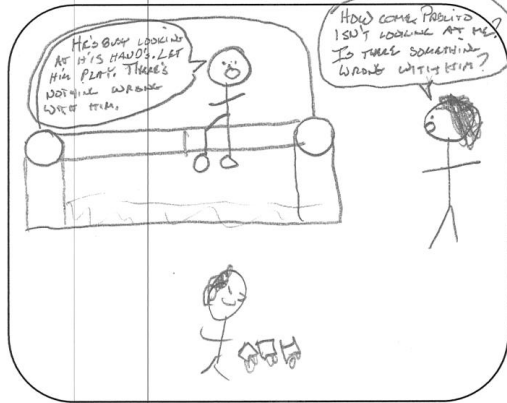
Box #4



#2
Scene: LIVING ROOM

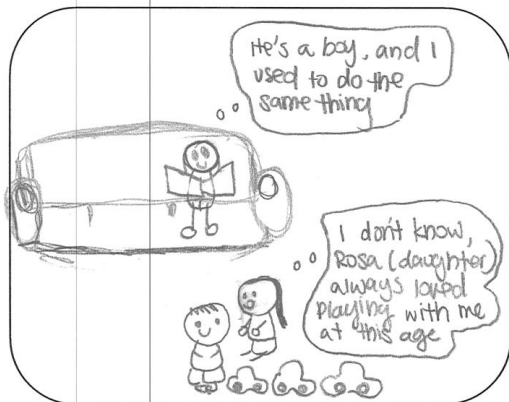
FELICE IS SITTING ON THE COUCH READING THE NEWSPAPER.

Box 5

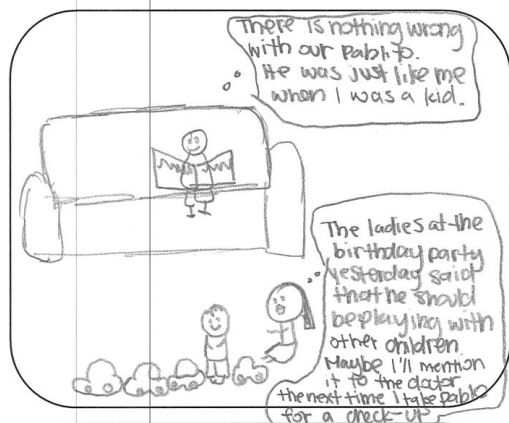


Scene: _____

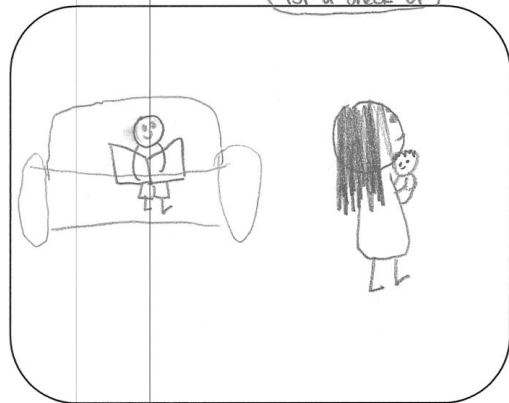
Box 6



Scene: 7

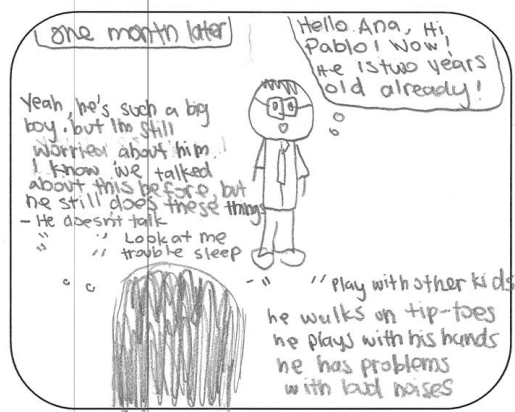


Scene: 8

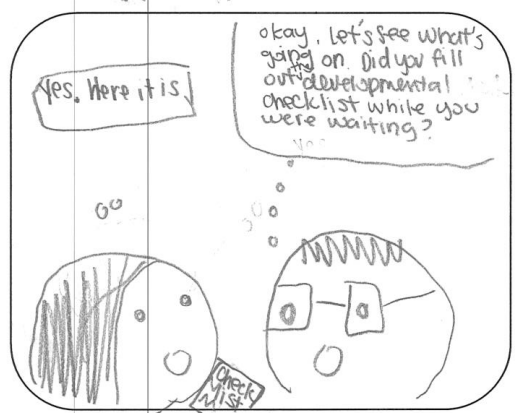


Scene: 9

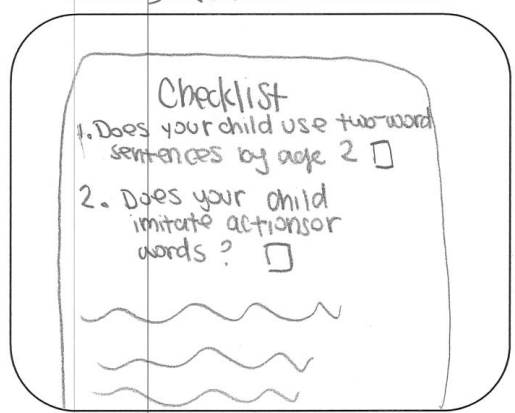
Ana walks away with Pablo while Felipe keeps reading the newspaper



Scene: 10 Scene 3



Scene: 11

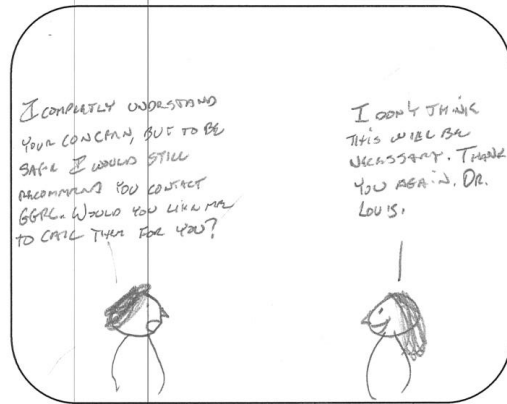


Scene: 12



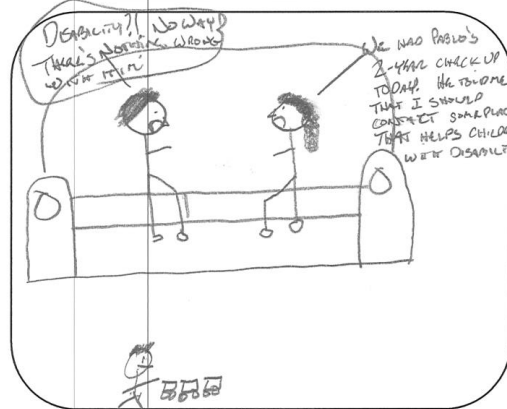
Scene: _____

Box 13



Scene: _____

Box 14

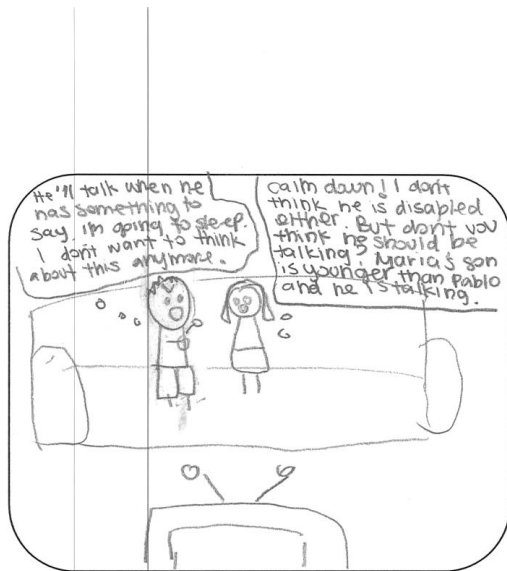


Scene: _____

Box 15

→ ANA AND FELIPA ARE SITTING ON THE COUCH TALKING

→ PABLO IS SITTING ON THE FLOOR Lining up cars on the floor



Scene: 16

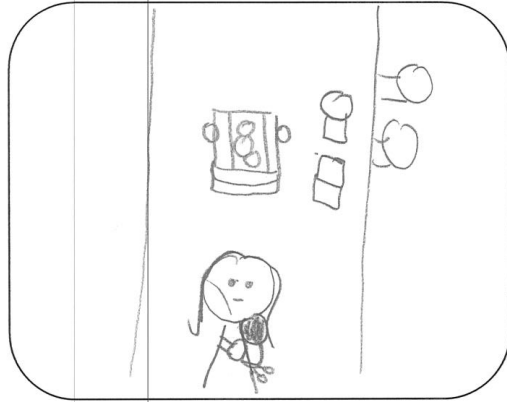


Scene: 17 Scene 5

Ana shopping
Pablo sitting in shopping
cart.



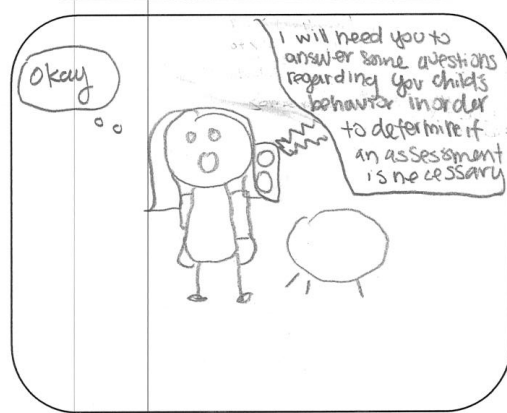
Scene: 18/19



Scene: 20
Ana embarrassed!



Scene: 21 Scene 6
GERC intake
 • Ana on the phone in the kitchen



Scene: 22



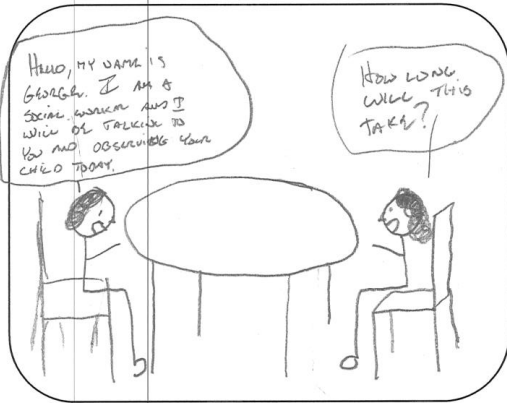
Scene: _____

Box 23



Scene: _____

Box 24



Scene: #7

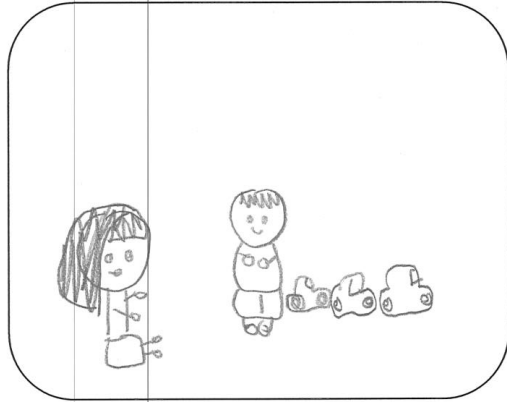
- Social Worker George and

and are talking to each other in the living room

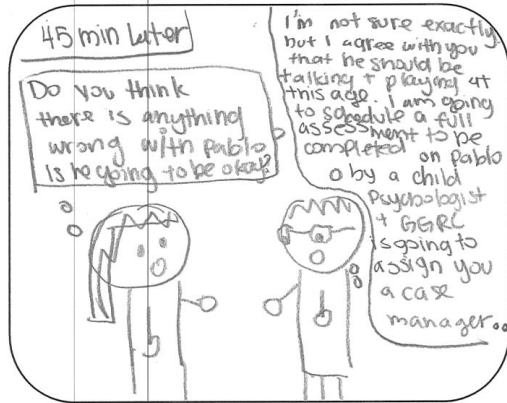
Box 25



Scene: 26



Scene: 27
Ana is sitting in the room
with Pablo.



Scene: 28



Scene: _____

Box 29



Scene: _____

Box 30



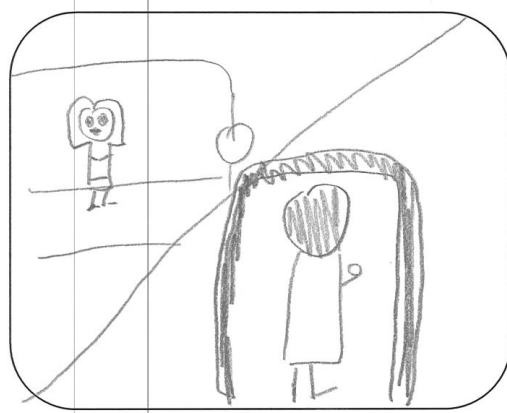
#8
Scene: _____

ANT AND FELIX
SITTING AT THE DINING
ROOM TABLE TALKING

Box 31



Scene: 32



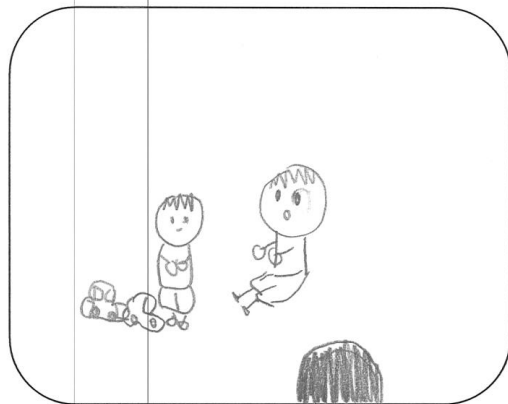
Scene: 33

Felipe leaves the room angry while Ana is sitting stunned by his response.

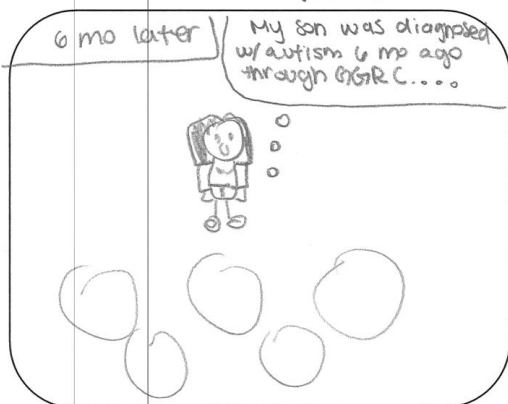


Scene: 34 scene 9

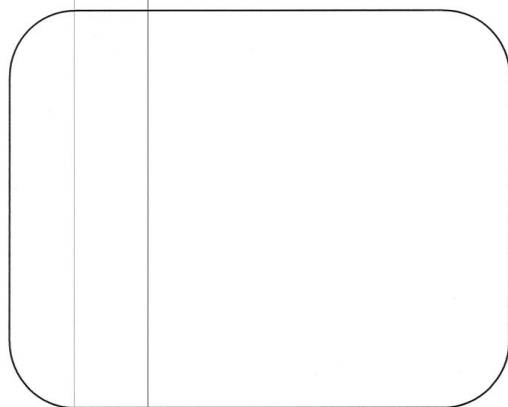
Psychologist office
45 days after
initial contact



Scene: 35
(Psychologist working Pablo
w/ Ana in the room
sitting there)



Scene: 36
6 mo later at
a support group for mothers



Scene: _____

La Historia de Pablo:

APRENDIENDO SOBRE EL AUTISMO

AUTORES: TIFFANY CHI,
MONICA GUZMAN CRITCHFIELD,
E I ISAAC STAHLHUT
CON STACY FRAUWIRTH, MS, OTR/L

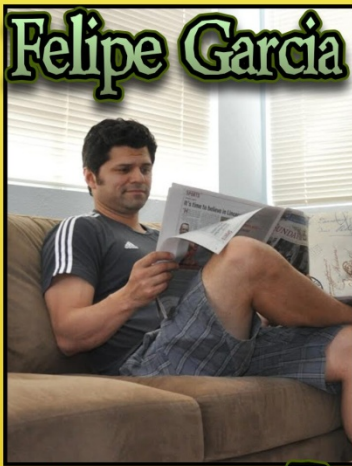


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& Dominican University of California**

LOS PERSONAJES



Ana García



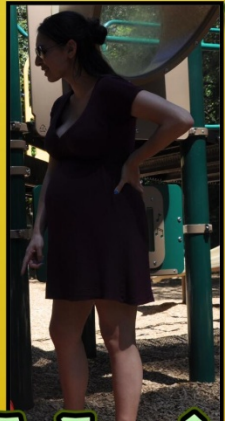
Felipe García



Pablo García

Dr. Louis

Brittany



María



Trabajadora Social
Heather



Psicólogo
David

FIESTA EN EL PARQUE: PABLO ESTÁ SENTADO EN EL PISO MIENTRAS QUE OTROS NIÑOS ESTÁN JUGANDO JUNTOS.



¿QUE PASA PABLO? ¿NO QUIERES JUGAR CON LOS OTROS NIÑOS?

OH, A ÉL LE GUSTA JUGAR SOLO. SE ENTRETENE BIEN.

¿JUEGA SOLO MUCHO?

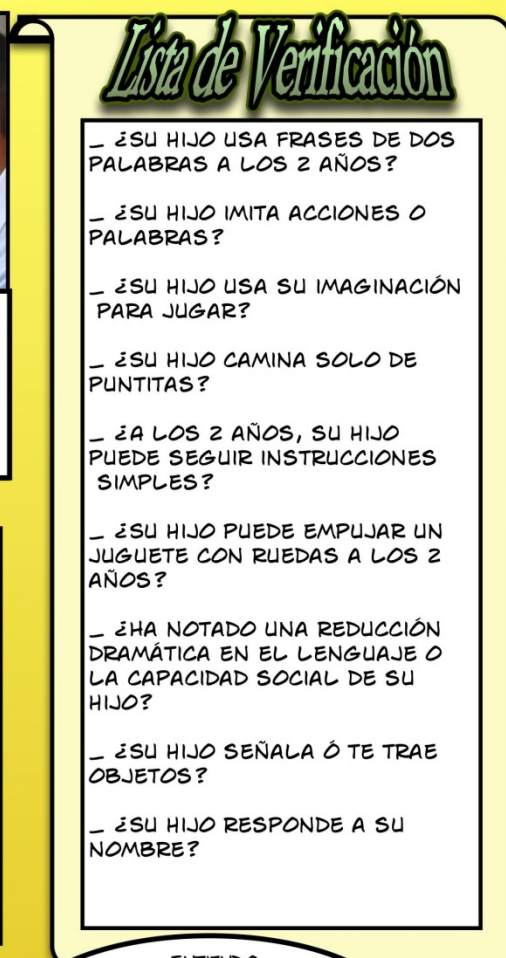
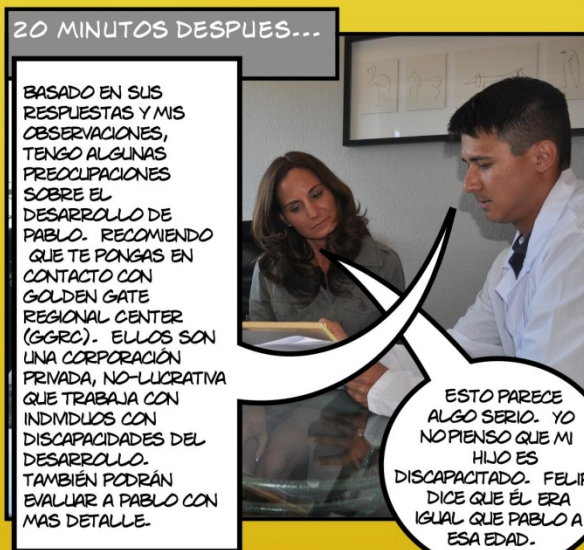


SI. ¿ES ALGO QUE ME DEBE DE PREOCUPAR?



¿LE PASA ALGO A MI PABLITO?







HOY DÍA TUVIMOS EL CHEQUEO DE 2 AÑOS PARA PABLO. EL DOCTOR ME DIJO QUE DEBO DE CONTACTAR UN SITIO QUE AYUDAN NIÑOS CON DISCAPACIDADES.

¿DISCAPACIDAD?!
¡NO ES POSIBLE! ¡NO PASA NADA CON ÉL!

¡CÁLMATE! YO TAMPOCO CREO QUE SEA DISCAPACITADO. PERO ¿NO PIENSAS QUE DEBÍA HABLAR YA? EL HIJO DE MARÍA ES MÁS JOVEN QUE PABLO Y ÉL ESTÁ HABLANDO.



HABLARÁ CUANDO TENGA ALGO QUE DECIR. ME VOY A DORMIR. YA NO QUIERO PENSAR MÁS SOBRE ESTO.



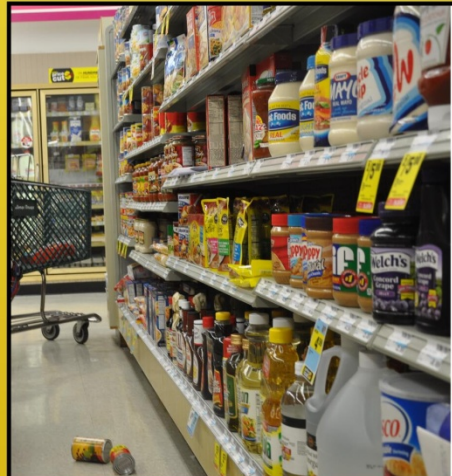
UN DÍA EN EL SUPERMERCADO...



¡AHHH!



¡AHHH!





(DENTRO DE 15 DIAS) SALA DE LA CASA DE LOS GARCIA



HOLA, MI NOMBRE ES HEATHER. YO SOY UNA TRABAJADORA SOCIAL Y HOY ESTARE HABLANDO CON USTED Y A OBSERVANDO SU HIJO.

¿CUANTO TIEMPO DURARÁ?



MÁS O MENOS DE 45 MINUTOS A UNA HORA.

OKAY, ESTÁ BIEN.



¿PIENSAS QUE ALGO PASA CON PABLO?

BASADA EN MI OBSERVACIÓN, SI TENGO PREOCUPACIONES ACERCA DEL DESARROLLO DE PABLO.



¿QUE PIENSAS QUE LE PASA? ¿VA A ESTAR BIEN?



MIL GRACIAS. ¿ESTO SERÁ GRATIS TAMBIÉN?

DE NADA. SI TODOS LOS SERVICIOS SON GRATIS.

NO ESTOY SEGURO EXACTAMENTE, PERO ESTOY DE ACUERDO QUE ÉL DEBERÍA ESTAR HABLANDO Y JUGANDO A ESTA EDAD. LE VOY HACER UNA CITA PARA UNA EVALUACIÓN COMPLETA PARA PABLO CON UN PSICÓLOGO DE NIÑOS Y GGRC LE ASIGNARÁ UN TRABAJADOR SOCIAL. ESTE TRABAJADOR SOCIAL COORDINARÁ UN PLAN DE SERVICIOS INDIVIDUALIZADOS PARA LA FAMILIA (IFSP). EL IFSP TENDRÁ LAS METAS PARA PABLO Y SU FAMILIA EN DETALLE. ESTE PLAN SERÁ COMPLETADO DENTRO 40 DÍAS DESDE SU PRIMERA LLAMADA A GGRC.





6 MESES DESPUÉS EN UN GRUPO DE APOYO PARA MADRES DE HIJOS CON AUTISMO.



Para más información

Si su hijo es menor de 3 años...

1. Se le asignará una trabajadora social para la evaluación y se le dará cita dentro de los 15 días hábiles después de suprimir contacto con Golden Gate Regional center para solicitar servicios. La cita puede ser en su casa o en el centro regional. En esta cita le darán información sobre el centro regional y sus servicios.
2. Si su hijo tiene entre 0 y 3 años, la evaluación para elegibilidad para servicios se hará dentro de los 45 días después de la primera cita. Además, dentro de los 45 días después del primer contacto con el centro regional, se completará para usted un plan llamado: Plan Familiar Individualizado de Servicios (IFSP por sus siglas en inglés).
3. El IFSP demostrará cómo se cumplirán las metas para su hijo de acuerdo a sus preferencias.

Si su hijo tiene más de 3 años...

1. Inscribalo en la escuela local o la oficina de educación del condado lo más pronto posible.
2. Informe a su escuela o la oficina de educación del condado que su hijo tiene necesidades especiales y está pidiendo una evaluación y programa apropiado para su hijo.
3. Traiga cualquier documento por escrito que tenga respecto a evaluaciones o programas durante el proceso de inscripción de su hijo.
4. Las evaluaciones ayudarán a desarrollar un plan individualizado de educación (IEP) para el niño.
5. El IEP demostrará cómo se cumplirán las metas para su hijo de acuerdo con sus preferencias y las de su hijo.

Página de Recursos

1. Golden Gate Regional Center

5725 Paradise Drive, Bldg. A, Ste. 100
Corte Madera, CA 94925
(415) 945-1600
Fax: (415) 945-1630

2. Matrix Parent Network and Resources

94 Galli Drive, Ste. C
Novato, CA 94949
415.884.3535 tel
800.578.2592 toll free
415.884.3555 fax

--Matrix Parent Network and Resources ofrece educación sobre recursos y servicios que existen para su niño con necesidades especiales.

3. Marin Special Education Local Plan Area - Marin County Office of Education

1111 Las Gallinas Ave.
P.O. Box 4925
San Rafael, CA 94913
(415) 499.5850

-- El SELPA de Marin ofrece educación pública apropiada y gratis para estudiantes con discapacidades en el ambiente menos restrictivo.

4. Child Development Center at California Pacific

Sutter Terra Linda Health Plaza
4000 Civic Center Dr., #210
San Rafael, CA 94903
(415) 492-4870

--El Centro de Desarrollo Infantil Kalmanovitz ofrece un programa completo de evaluación y tratamiento para bebés, niños y adolescentes.

5. Centro de Autismo y Desarrollo Neurológico, University of California, San Francisco

401 Parnassus Avenue
San Francisco, CA 94143-0984
(415) 476-7500

-- Los servicios incluyen evaluación clínica, evaluación genética, evaluación neurológica y tratamiento.

6. La Cooperativa de Autismo en Marin (MAC)

899 Northgate Drive, Suite 500
San Rafael, CA 94903
(415) 472-2373

www.marinautism.org

Pablo's Story:

LEARNING ABOUT AUTISM

BY: TIFFANY CHI, MONICA GUZMAN CRITCHFIELD,
& ISAAC STAHLHUT
WITH STACY FRAUWIRTH, MS, OTR/L

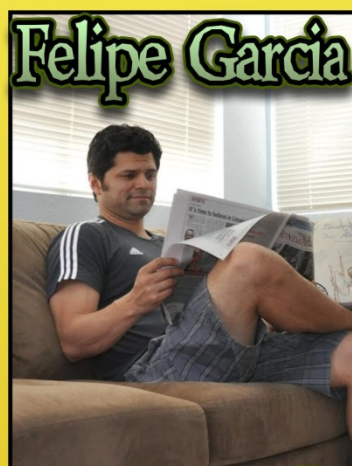


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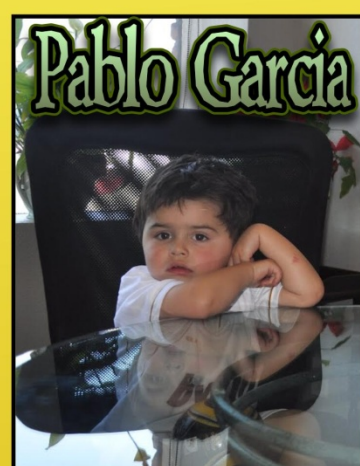
MEET THE CHARACTERS



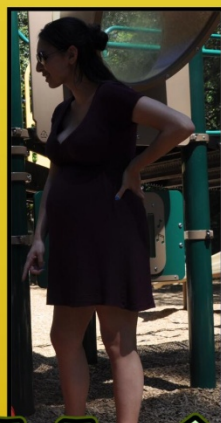
Ana Garcia



Felipe Garcia



Pablo Garcia



Maria



Dr. Louis



Social Worker
Heather



Brittany



Psychologist
David

BIRTHDAY PARTY AT THE PARK: PABLO IS SITTING ON THE GROUND ALONE WHILE THE OTHER CHILDREN PLAY TOGETHER.



WHAT IS WRONG WITH PABLO? WHY ISN'T HE PLAYING WITH THE OTHERS?

OH. HE LIKES TO PLAY BY HIMSELF. HE ENTERTAINS HIMSELF WELL.

DOES HE PLAY BY HIMSELF A LOT?



YEAH... HE DOES. IS THAT SOMETHING I SHOULD WORRY ABOUT?



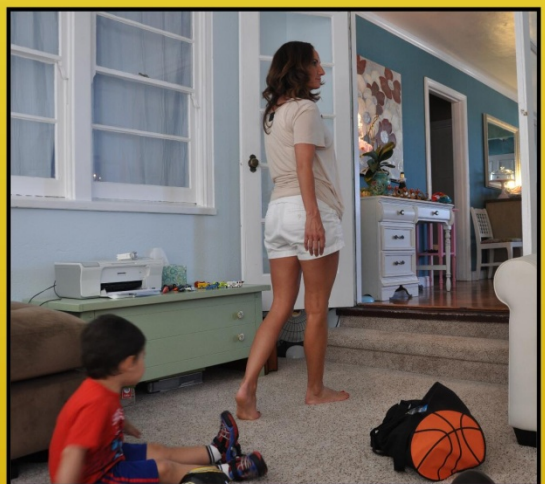
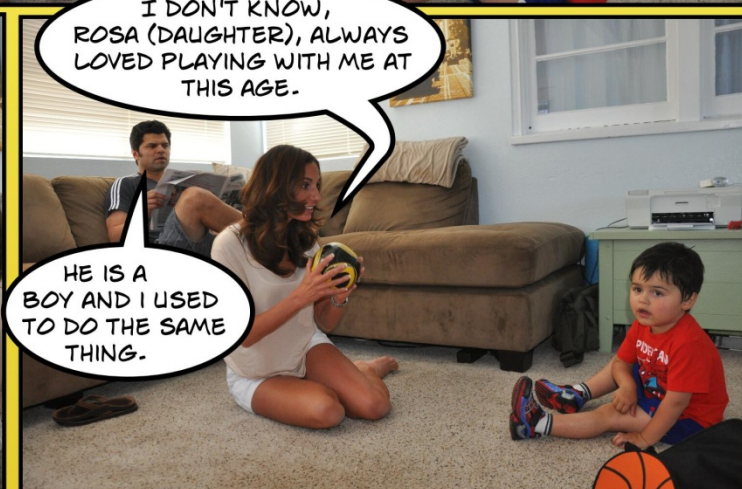
IS THERE SOMETHING WRONG WITH MY PABLITO?



LIVING ROOM OF THE GARCIA'S HOME.



HE IS BUSY LOOKING AT HIS HANDS. LET HIM PLAY THERE IS NOTHING WRONG WITH HIM.





ONE MONTH LATER...

HI ANA, HI PABLO! WOW! HE IS TWO YEARS OLD ALREADY!

YEAH, HE'S SUCH A BIG BOY, BUT I'M STILL WORRIED ABOUT HIM. I KNOW WE TALKED ABOUT THIS BEFORE, BUT HE STILL DOES THESE THINGS: HE DOESN'T TALK, LOOK AT ME, PLAY WITH OTHER KIDS, HE HAS TROUBLE SLEEPING, HE WALKS ON HIS TIP-TOES, HE PLAYS WITH HIS HANDS, AND HE HAS PROBLEMS WITH LOUD NOISES.

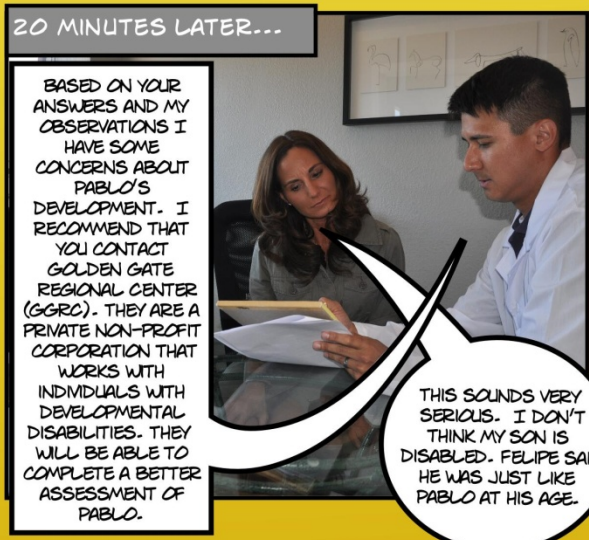


OKAY. LET'S SEE WHAT'S GOING ON. DID YOU FILL OUT THE DEVELOPMENTAL CHECKLIST WHILE YOU WERE WAITING?

YES. HERE IT IS.

Checklist

- DOES YOUR CHILD USE TWO-WORD SENTENCES BY AGE 2?
- DOES YOUR CHILD IMITATE ACTIONS OR WORDS?
- DOES YOUR CHILD PRETEND PLAY?
- DOES YOUR CHILD WALK ONLY ON THEIR TOES?
- DOES YOUR CHILD FOLLOW SIMPLE INSTRUCTIONS BY AGE 2?
- CAN YOUR CHILD PUSH A WHEELED TOY BY AGE 2?
- DID YOUR CHILD EXPERIENCE A DRAMATIC LOSS OF LANGUAGE OR SOCIAL SKILLS THEY ONCE HAD?
- DOES YOUR CHILD POINT OR BRING OBJECTS TO YOU?
- DOES YOUR CHILD RESPOND TO HIS/HER NAME?



20 MINUTES LATER...

BASED ON YOUR ANSWERS AND MY OBSERVATIONS I HAVE SOME CONCERNS ABOUT PABLO'S DEVELOPMENT. I RECOMMEND THAT YOU CONTACT GOLDEN GATE REGIONAL CENTER (GGRC). THEY ARE A PRIVATE NON-PROFIT CORPORATION THAT WORKS WITH INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES. THEY WILL BE ABLE TO COMPLETE A BETTER ASSESSMENT OF PABLO.

THIS SOUNDS VERY SERIOUS. I DON'T THINK MY SON IS DISABLED. FELIPE SAID HE WAS JUST LIKE PABLO AT HIS AGE.



I COMPLETELY UNDERSTAND YOUR CONCERN, BUT TO BE SAFE I WOULD STILL RECOMMEND YOU CONTACT GGRC. WOULD YOU LIKE ME TO CALL THEM FOR YOU?

I DON'T THINK THIS WILL BE NECESSARY. THANK YOU AGAIN DR. LOUIS.







(WITHIN 15 DAYS) LIVING ROOM OF THE GARCIA'S HOUSEHOLD



HELLO, MY NAME IS HEATHER. I AM A SOCIAL WORKER AND I WILL BE TALKING TO YOU AND OBSERVING YOUR CHILD TODAY.

HOW LONG WILL THIS TAKE?



ABOUT 45 MINUTES TO AN HOUR.

OKAY. SOUNDS GOOD.



DO YOU THINK THERE IS ANYTHING WRONG WITH PABLO?

BASED ON MY OBSERVATION I DO HAVE CONCERNS ABOUT PABLO'S DEVELOPMENT.



WHAT DO YOU THINK IS WRONG WITH HIM? IS HE GOING TO BE OKAY?

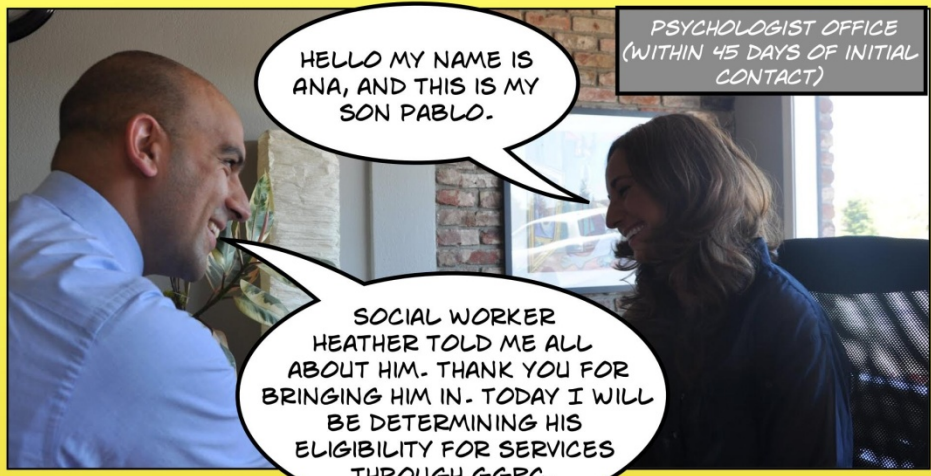
I'M NOT SURE EXACTLY, BUT I AGREE WITH YOU THAT HE SHOULD BE TALKING AND PLAYING AT THIS AGE. I AM GOING TO SCHEDULE A FULL ASSESSMENT TO BE COMPLETED ON PABLO BY A CHILD PSYCHOLOGIST AND GGRC IS GOING TO ASSIGN YOU A CASE MANAGER. THIS CASE MANAGER WILL SET UP A INDIVIDUAL FAMILY SERVICE PLAN (IFSP). THIS WILL DETAIL THE GOALS THAT YOU HAVE FOR PABLO AND YOUR FAMILY. THIS PLAN WILL BE COMPLETED WITHIN 45 DAYS OF YOUR FIRST PHONE CALL TO GGRC.



THANK YOU SO MUCH AND WILL THIS BE FREE ALSO?

YOU'RE WELCOME, YES, ALL THESE SERVICES ARE FREE OF CHARGE.





(6 MONTHS LATER AT A SUPPORT GROUP FOR MOTHERS OF CHILDREN WITH AUTISM)



Additional information

IF your child is under age 3...

1. An Assessment Social Worker will be assigned to you and will schedule the first appointment within 15 working days after initially contacting Golden Gate Regional Center for services. The appointment will be held at your home or at the regional center. At this appointment, your family will be given information about the regional center and about their services.

2. If your child is between ages 0-3, assessments for eligibility of services are performed within 45 days following the first appointment. In addition, a plan called Individual Family Service Plan (IFSP) is completed within 45 days of the family's first contact with the regional center.

3. The IFSP helps show you how goals for your child will be met as preferred by you and your family.

IF your child is age 3 or above...

1. Immediately enroll your child into the local school or county office of education as soon as possible.

2. Inform the local school or county office of education that your child has special needs and are requesting assessment and placement appropriate for your child.

3. Bring any written request for assessments and placement during the process of enrolling your child into the new school.

4. Assessments will help develop an Individualized education plan (IEP) for the child.

5. The IEP helps show how your child goals will be met as preferred by you and your child.

Resource list

1. Golden Gate Regional Center

5725 Paradise Drive, Bldg. A, Ste. 100
Corte Madera, CA 94925
(415) 945-1600
Fax: (415) 945-1630

2. Matrix Parent Network and Resources

94 Galli Drive, Ste. C
Novato, CA 94949
415.884.3535 tel
800.578.2592 toll free
415.884.3555 fax

--Matrix Parent Network and Resources provides parent education on resources and services available for child with special needs.

3. Marin Special Education Local Plan Area - Marin County Office of Education

1111 Las Gallinas Ave.
P.O. Box 4925
San Rafael, CA 94913
(415) 499.5850

-- The Marin SELPA will provide free, appropriate public education to students with disabilities in the least restrictive environment.

4. Child Development Center at California Pacific

Sutter Terra Linda Heath Plaza
4000 Civic Center Dr., #210
San Rafael, CA 94903
(415) 492-4870

-- The Kalmanovitz Child Development Center offers a comprehensive assessment and treatment program for infants, preschoolers, school-age children and adolescents.

5. University of California, San Francisco, Autism and Neurodevelopment Center

401 Parnassus Avenue
San Francisco, CA 94143-0984
(415) 476-7500

-- Services include: Clinical Assessment, Genetic Evaluation, Neurological Evaluation and Treatment.

6. Marin Autism Collaborative (MAC) at Lifehouse

899 Northgate Drive, Suite 500
San Rafael, CA 94903
(415) 472-2373

www.marinautism.org

APPENDIX H

POST-Evaluation de la Fotonovela sobre el autismo**1. La historia fue facil entender.**

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

2. La información sobre autismo es útil.

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

3. El formato de la *fotonovela* fue culturalmente relevante.

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

4. Con base en la información de la página de recursos, yo sabría a quién llamar para obtener información.

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

5. Yo recomendaría esta fotonovela a otras familias de niños con autismo.

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

6. La fotonovela fue visualmente atractivo.

Muy de acuerdo – 5 – 4 – 3 – 2 – 1 – Muy en Desacuerdo

COMENTARIOS / RECOMENDACIONES

|

POST-Evaluation of the *Fotonovela*

1. The story was easy to understand.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

2. The information about autism was helpful.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

3. The format of the *fotonovela* was culturally relevant.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

4. Based on the information on the resource page I would know who to call for information.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

5. I would recommend this *fotonovela* to other families of children with autism.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

6. The *fotonovela* was visually appealing.

Strongly Agree – 5 – 4 – 3 – 2 – 1 – Strongly Disagree

Comments: _____

COMMENTS / RECOMMENDATIONS:

Is there anything else you would like to tell us about the *fotonovela*.

Thank you for your response. All responses are confidential and are used for evaluation purposes only.

APPENDIX I

All information must be typed. Handwritten applications will be returned to the project leader.

Thesis Project Proposal Form

Name (s): Tiffany Chi, Monica Guzman, & Isaac Stahlhut

E-mail address(es):

Phone Contact(s):

Thesis advisor information:

Name: Stacy Frauwirth

Campus Phone: _____

E-mail address: _____

Project Information:

Proposed title of project: Fotonovelas: A parent resource and education guide for underserved Latinos families with autism in Marin County

Contact Person at Agency/Setting: Karen Kaplan

Phone Number of Contact & email: _____

Duration of Project: Spring 2012- Fall 2012

What problem will be addressed with this project: (no more than 300 words).

Describe the nature of this project, the problem addressed and the purpose of the project:

The nature of the project is to create a resource guide to provide services and education for underserved Hispanic families with autism in the form of a fotonovela. The resource guide will educate families to recognize signs and symptoms of autism. It will also provide them with resources that they can access in the Marin County.

What are current approaches to this problem. Describe what approaches are being used to solve this problem.

There are no direct approaches available to help underserved Hispanic families identify signs and symptoms of Autism. For these families, the signs and symptoms of autism are often recognized by pediatricians, teachers, or by people around the community. There are also websites that educate families on how to recognize these signs and symptoms, but it is found that underserved families cannot directly access it because of the limited access in their environment.

Description of participants and agency/setting.

The participants are underserved Hispanic families with children with autism. MAC will distribute this resource guide around Marin County.

Recruitment Procedure. Indicate how applicant will approach the agency/Setting (face-to-face, phone contact, mail, email, etc) along with copies of materials used to contact or recruit individuals at the setting and permission letters if applicable.

MAC will distribute copies of the fotonovela to various settings around Marin County where underserved Hispanics congregate. Some examples of the settings are: hospitals, churches, day-care centers, The Novato Youth Center, Matrix, and various Autism fairs that will take place in the Marin County.

Setting/Participant Consent Process: Attach Informed Consent Forms if they are to be used with this project. If consent forms are not to be used explain why and provide copy of Consent Cover Letter.

Procedures. Describe in detail what your project will require of participants, what they will experience and include copies of all written materials participants may see (surveys, questionnaires, interview questions, teaching materials, etc.).

To produce the fotonovela several steps are going to be taken before creating the final product. To begin, we will create and list some questions that we will administer during a focus group. The questions we will ask the families will involve the hurdles and barriers they encountered during their attempt to receive services for their child. These questions will include the steps they needed to take to get their child diagnosed, who they spoke to after their diagnosis, and which services were the most helpful for them and their child.

With the questions in hand, we will contact Matrix to request permission to participate in one of their autism support groups; the request will also include permission to perform a focus group. The questions that we will create will be asked during the focus group to the audience. The answers we receive from the focus group will provide the foundation to create the overall story for the fotonovela.

The participants from the focus groups are going to be asked to further volunteer their time to participate and offer a detailed narrative in the process of receiving services for their child. Three narratives are going to be chosen, recorded and transcribed by a Spanish translator. The stories will be transcribed by a professional from Spanish to English.

From the three stories that will be collected, we will create a one story incorporating important information from each of the stories. Using the story created, a storyboard is going to be generated. This storyboard is going to be used to generate the basic outline for the fotonovela.

Recruitment of actors will also be needed for the pictures that are going to be taken for the fotonovela. A professional photographer is going to be hired prior to the recruitment of the models. The actors that will be recruited will vary from other students in the program to the participants that will volunteer to tell us their story. The actors and actresses will play the part of friends, family members, doctors, and counselors in the pictures for the fotonovela.

The recruited actors will model different scenarios that will be created from the storyboard. The photos taken will be uploaded into a computer to where they were manipulated into a program called "Comic Life" for a Macintosh computer. Within this computer program the dialogue will be added to the pictures so that the story could be

conveyed from page to page.

The rough copy of the fotonovela is going to be sent to MAC for approval. Along with approval of the fotonovela, a list of autism resources will be compiled by MAC, which will be added to the last page of the fotonovela. With the resource page and approval from MAC, final copies are going to be published for distribution using the money that will be hopefully granted to this project by Autism Speaks.

Potential Risk to Participants. Describe all potential risks to participants (falls, emotional distress, etc.). Applications that do not address risks will be returned.

Emotional distress is a possible risk for the participants because during the focus group interviews, they will be retelling their personal story of their first encounter with autism.

Minimization of Potential Risk. Describe ways the potential risks will be minimized by the leader(s) of the project.

To minimize the potential risks for the participants, the leaders can provide empathy toward the families' stories. In addition, the leaders can also remind the participants that by retelling their own story, they can help other underserved Hispanic families that are going through similar situations.

Potential Benefits to Participants. Describe in detail all potential benefits to the individual participant and the setting.

MAC will benefit from the fotonovela because it will help them efficiently educate underserved Latino families of the signs and symptoms of autism. Fotonovela is appropriate to use because it is popular cultural medium that appeals to the Hispanic culture. It is also an education tool that has been used in the past to educate Hispanic families about different health issues. The fotonovela will be easily accessed without the use of computers because it will be located at different locations in which the underserved Hispanics commonly congregate. The fotonovela will provide scenarios and information in an easy to understand format for underserved Hispanic families. The participants can benefit from the fotonovela because it will help them recognize signs of symptoms early in their children's lives. This will help them locate early intervention services to help their child with their deficits. The fotonovela will also guide them to accessible resources in the Marin County.

Intended Outcomes of the Project. Describe what outcomes you intend to come from this project. What follow-up or future planning do you suggest?

We want to develop this fotonovela, a dramatic photo book media, in hopes that it will educate and provide resources to underserved Hispanic families of the signs and symptoms of autism. This will help the families access early intervention services in their children's life to enhance their occupations.

What are the Project Deliverables. Describe what you will deliver to the agency or setting when you are finished with this project.

We will deliver finished copies of the fotonovela to MAC.

Costs to Participants. Describe any costs to participants (transportation, time, effort, etc.).

There are no costs for the participants. We will only ask of the participants their time to tell their detailed story and, if they participate, their time to take photographs for the fotonovela

Reimbursement or Compensation to Participants: Describe and provide rationale for any reimbursement or compensation in response to participation in the research.

No reimbursement will be made.

Confidentiality of Records:

Check which of the following applies:

Data will be anonymous

Describe how anonymity will be ensured.

Data will not be anonymous

Describe how data will be kept confidential? Who will see it?

The names of the focus group participants will be anonymous. The story collected in the focus group will be seen by transcribers, the project creators, and the thesis advisor.

Describe where data will be stored

The data collected in the focus group will be stored in a locked box in the project creator's home office.

Describe how participant identify will be kept separate from participant data.

The participant's data and the participants' identity will be kept in different boxes. Each box will be kept by a different project creator in the group.

Signatures:

I acknowledge that all procedures will meet relevant local, state, and federal regulations related to the setting and participants. I am familiar with and agree to adhere to the ethical principles set forth by AOTA.

Signature of Applicant

Date

Signature of Applicant

Date

Signature of Applicant

Date