

2011

# A PROPOSED ASD-CENTRIC COLLABORATIVE TREATMENT ENVIRONMENT: THE UNDERLYING ROLE OF VIRTUAL CARE TEAMS

Panagiotis Germanakos

*Institute of Informatics and Telematics (IIT), pgerman@cs.ucy.ac.cy*

Dimosthenis T. Georgiadis

*University of Nicosia, georgiadis.d@unic.ac.cy*

Marina Buzzi

*Institute of Informatics and Telematics (IIT), marina.buzzi@iit.cnr.it*

Maria Claudia Buzzi

*Institute of Informatics and Telematics (IIT), claudia.buzzi@iit.cnr.it*

Claudia Fenili

*ASA (Associazione Sindromi Autistiche), Sesto Fiorentino (FI), claudiafenili14@libero.it*

Follow this and additional works at: <http://aisel.aisnet.org/mcis2011>

## Recommended Citation

Germanakos, Panagiotis; Georgiadis, Dimosthenis T.; Buzzi, Marina; Buzzi, Maria Claudia; and Fenili, Claudia, "A PROPOSED ASD-CENTRIC COLLABORATIVE TREATMENT ENVIRONMENT: THE UNDERLYING ROLE OF VIRTUAL CARE TEAMS" (2011). *MCIS 2011 Proceedings*. 8.

<http://aisel.aisnet.org/mcis2011/8>

This material is brought to you by the Mediterranean Conference on Information Systems (MCIS) at AIS Electronic Library (AISeL). It has been accepted for inclusion in MCIS 2011 Proceedings by an authorized administrator of AIS Electronic Library (AISeL). For more information, please contact [elibrary@aisnet.org](mailto:elibrary@aisnet.org).

# A PROPOSED ASD-CENTRIC COLLABORATIVE TREATMENT ENVIRONMENT: THE UNDERLYING ROLE OF VIRTUAL CARE TEAMS

Germanakos, Panagiotis, Institute of Informatics and Telematics (IIT), CNR, Via Giuseppe Moruzzi 1, 56124, Pisa, Italy, pgerman@cs.ucy.ac.cy

Georgiadis, Dimosthenis, Department of Management & MIS, University of Nicosia, 46 Makedonitissas Ave., 1700 Nicosia, Cyprus, georgiadis.d@unic.ac.cy

Buzzi, Marina, Institute of Informatics and Telematics (IIT), CNR, Via Giuseppe Moruzzi 1, 56124, Pisa, Italy, marina.buzzi@iit.cnr.it

Buzzi, Maria Claudia, Institute of Informatics and Telematics (IIT), CNR, Via Giuseppe Moruzzi 1, 56124, Pisa, Italy, claudia.buzzi@iit.cnr.it

Fenili, Claudia, ASA (Associazione Sindromi Autistiche), Sesto Fiorentino (FI), Italy, claudiafenili14@libero.it

## Abstract

*Every year an increasing number of individuals are diagnosed with Autism Spectrum Disorder (ASD). ASDs involve difficulties with self-initiation of social behaviors, possibly due to motivational issues, as well as language and behavioral impairments. Given the complexity and the abnormal development of this disorder one-to-one multidisciplinary treatment approach under a common dynamic collaborative environment is considered of paramount significance. This paper proposes an ASD-centric Computer Supported Collaborative Treatment Environment/model which employs the notion of Virtual Care Teams for supporting continuous treatment and service provision adopted on the unique qualities, interests, personality traits and contextual characteristics of a person with ASD. Furthermore, it proposes a set of services adjusted to the peculiarities and values of the ASD field. With the successful implementation of this collaboration model, an increased communication, effective decision making and prompt error handling can be achieved to the benefit of the individual with ASD; that is, increase to its intellectual capabilities, social inclusion, and self-motivation.*

*Keywords: eHealth, Autistic Spectrum Disorders, Collaboration Services, Virtual Care Teams.*

# 1 INTRODUCTION

Autistic Spectrum Disorders (ASDs) is a pervasive developmental disorder marked by social and communication impairments, along with repetitive activity patterns. According to the EU Autism Action 2010, the ASD is a significant public health challenge. Current estimates are that approximately 1% of the US and UK population has ASD, which, if one were to extrapolate, means five million people in EU member state countries are on the autism spectrum. People with classical autism show three types of symptoms: (a) impaired social interaction, (b) problems with verbal and non-verbal communication and imagination, and (c) unusual or severely limited activities and interests (Volkmar, 2005). Symptoms usually appear during the 2-3 years of childhood and continue throughout life with unusual developmental patterns (Landa et al., 2006; Lord et al., 2006). Moreover, people with autism often interpret situations differently from non-autistic people and struggle with new, unpredictable and ambiguous environments. This affects how they manage in a range of situations and settings such as schools, hospitals, markets, the workplace, etc. Although people with autism share some common characteristics (such as abnormal interpersonal communication, deviant social interaction, atypical behavior characteristics, and unusual patterns of attention and learning characteristics), no two individuals are the same. In addition, the pattern and extent of difficulties may change with development (i.e. learning disabilities and/or mental illnesses, such as depression and anxiety). Given this evolving nature of diagnoses over time for autistic persons as well as the unpredicted behaviors and responses on particular sensor stimuli the treatment method should be dynamic and adapted always in persons' with ASD current state. It is generally agreed that no single intervention will suit all people with autism, and also, any intervention can have negative as well as positive effects. No one approach is appropriate for all individuals on the autism spectrum or even for the same individual across his/her lifespan (National Research Council, 2001). Choosing an intervention can be a difficult task as there are many different options available (a range of interventions have been developed. i.e. behavioral methods, education-based approaches and non-verbal communication systems, Koegel et al., 1995; Lindblad, 1996), and it is often difficult to determine which interventions will best suit an autistic person. Individuals with ASD need personalized designed interventions which are dynamically adapted to their situation and not what is available in the market that may not meet their needs, which is sometimes the case (National Research Council, 2001).

Nevertheless, no intervention can have an actual effect, if there is not a comprehensive and continuous synergy among the involved parties around the autistic person's treatment (i.e. family, teachers, therapists, psychologists, social workers, etc.), in a well-coordinated, pragmatic, and consistent manner; with a continuous exchange and update of related information and services. These services should be ASD-individual-centric considering all its distinctive personality factors, strengths and weaknesses as well as context characteristics. The use of latest technological advancements has shown that are able to increase social interaction in persons with ASD, even though that effect requires further study to be constantly employed as a therapeutic intervention (Moore, 1998). Similarly, with the use of technology-based collaborative environments and systems we could implement sound and effective applications with regards to a person's with ASD development and monitoring. In recent years, there is an increasing number of researches and studies in Computer Supported Cooperative Work (CSCW) applications and systems in a variety of fields, i.e. eHealth (Georgiadis et al., 2007) and Ambient Assisted Living (Christodoulou et al., 2010), which reveal encouraging results with regards to treatment and social inclusion of patients and elderly people accordingly. In this respect, main purpose of this work is to propose and analyze an ASD-centric Computer Supported Collaborative Treatment Environment (ASD-centric CSCTE). The particular model aims to identify the services and collaboration dynamics among the prospective bodies that involved in the treatment of persons with ASD. Given the one-to-one treatment and therapy applied in such cases this approach will enhance decision-making through collaboration and a 24/7 synchronous exchange of information with regards to the person's with ASD state that will enable the successful control of its situation.

The remainder of this paper is organized as follows: In section 2 we present an overview of the ASD characteristics and treatment approaches, while we stress emphasis upon the collaboration issues and attempts that have been undertaken. In section 3 we introduce the notion of Virtual Care Teams which has been employed as the core element of our proposed collaboration treatment model, analyzed in section 4. In section 5 we outline a real life scenario of a child with ASD, namely Dado, which utilizes the proposed collaborative environment and the suggested services. Section 6 concludes this paper.

## **2 BACKGROUND WORK**

### **2.1 ASD and Treatment Approaches**

Autism is a brain disorder that makes it hard for a person to communicate and interact with others. It is the most common of a group of related disorders called Autistic Spectrum Disorders (ASDs), with the next most common autistic spectrum disorder the Asperger's syndrome. ASD affect people differently and to different degrees. Symptoms and behaviors can vary, ranging from mild to severe. ASD is characterized by: (i) qualitative impairments in social interaction shown by abnormalities in such behaviors as eye gaze, body posture, sharing interests and emotions; (ii) qualitative impairments in communication shown by language development issues such as delayed status, problems initiating and sustaining conversations, repetitive patterns; and (iii) a restricted repertoire of interests, behaviors and activities shown by an adherence to certain topics, routines, rituals, motor manners, parts of objects and sensory abnormalities (Charman & Baird, 2002). Autism was first identified in 1943, but we still do not know what causes it. Since people are either born with autism or have the potential to develop it, scientists are studying both genetic and environmental factors (Bailey, 1995), with no, however, proven links between vaccines and autism.

The Diagnostic and Statistical Manual, 4th edition, Text Revision published by the American Psychiatric Association (DSM-IV TR, 2000) is the current standard for the diagnosis and classification of ASDs by health or mental health professionals. The multiple developmental challenges, associated problems, symptom presentation and degree of impairment can vary not only among individuals but also within the same individual over time. The complexity of these disorders necessitates a range of services that are tailored to the needs of families and the individual with ASD, from screening and referral services through diagnosis, assessment for intervention planning, and treatment. Specific standardized instruments are available that aid the clinician in gathering relevant information and evaluating specific ASD impairments (Bryson et al., 2003; Pinto-Martin et al., 2009). Research has demonstrated that the use of these instruments adds incremental value to diagnostic accuracy (Lord et al., 2006). The comprehensive evaluation of a child with a suspected ASD may include speech, language, and communication assessments, cognitive testing, behavioral assessments, academic assessments, and a medical evaluation (Filipek et al., 2000). The identification of the exact condition of the individual with ASD is critical, in order for the appropriate intervention planning to be formulated, and the suitable treatment and services to be initiated immediately based on its strengths and personality traits. All individuals diagnosed with ASD are assessed, for intervention planning, in the following domains: cognitive and academic functioning; adaptive functioning; social, emotional, and behavioral functioning; communication; comprehensive medical examination; sensory and motor functioning; and family functioning. Assessment in each component is based on family concerns, clinical indicators, the individual's intervention history, and data available from prior assessments. Additional clinical assessment that is needed for intervention planning depends on the nature of the diagnostic evaluation (Filipek et al., 2000; American Academy of Pediatrics, 2001). There are many studies that have analyzed and categorized a series of intervention methods that could support individuals with ASD. Indicatively, according to Ruble and Akshoomof (2010), primary interventions for children with ASD include educational and behavioral approaches, while Young et al. (Young et al., 2010), have been proposed a three level approach to interventions for children (based on the National Professional Development Center's (NPDC) criteria for assessing evidence-based practices): Level-1: Evidence-Based Interventions, level-2: Emerging Evidence-Based Interventions, and level-3: Unestablished interventions. The particular interventions have been standardized and applied to

Transitioning Youth and Adults categories, with the adequate variations and classifications among the three levels according to the category of examination.

According to several studies (Anderson & Romanczyk, 1999; Corsello, 2005), early intervention in persons with ASD is more effective for learning and developing social abilities (Howlin, 2008; Rogers & Vismara, 2008). It is very important to act quickly in the first two years of life while often autism symptoms appear at 18-36 months, and some alarming signals may be observed very early, from birth. A substantial benefit also of early intervention is the positive impact on the family's ability to interact in a manner that facilitates and copes with their child's developmental concerns, and the greater understanding of their child's disability and how it interacts with family life (Committee on Children with Disabilities, 1994). Hence, families have to work collaboratively with professionals from i.e. school, community and special education, to integrate the various assessment findings into a comprehensive profile of the individual's strengths and concerns. This profile becomes the family's basis for planning for the selection of specific interventions.

## **2.2 Collaboration Issues and Attempts Supporting Individuals with ASD**

There is a broad consensus in the ASD research area that generalization of application methods and approaches in the individuals' with ASD treatment is neither feasible nor effective. Even though two such persons are in the same age, diagnosed with the same symptoms, strengths, characteristics and interests, the dynamic complicated nature (unusual developmental patterns) of this disorder does not suggest that these persons will react or behave similarly in front of a particular stimuli or intervention. Therefore, a highly individualized and intensive treatment could have the most positive impact on the abilities of an individual with autism, applied on a continuous basis and with a tight synergy among the involved care parties. Assessment and treatment is an interchanging ongoing process. Even though it is possible for an independent professional or professionals representing one or two areas of expertise to make an ASD diagnosis, assessment for intervention planning requires involvement of professionals representing multiple disciplines. Due to the complexity of these disorders, a comprehensive, multidisciplinary assessment process involving professionals representing diverse fields of study (i.e. therapists, special teachers, consultants, physicians, psychologists, social workers, etc.) and the individuals' parents is required to make the diagnosis of an ASD and to develop and implement an appropriate treatment plan (Kerrell, 2001; Volkmar et al., 1999). This synergy can promote discussion among the involved parties and add value to the collective expertise and the common perspective of the interdisciplinary team, to ensure that the many needs of these individuals are met across multiple settings, and the identification of the best course of action has been framed (Power et al., 2003). Although a variety of service models have been described that focus on collaboration among medical and educational service professionals (Drotar et al., 2004), one important component that should embrace all these models is the reliance on the shared updated data and continuous support (mostly due to the fact that many of these persons are unable to communicate either the symptoms they experience or distress that is associated with i.e. headaches, stomachaches, etc., or other predispositional effects that grounded based on the prompting surrounding environment or particular stimuli) to update decision making and treatment planning. This collaboration and involvement allows for management and modification of treatment plans over time (Shellenberger & Couch, 1984) and the provision of more accurate and comprehensive set of services.

The approaches that embrace these critical collaboration issues for developing a sound cooperative treatment environment around an individual with ASD vary considerably. More broadly, we could say that these are distinguished to technology-based and non-technology-based. The latter category involves mostly attempts that try to strengthen the parent-teacher relationship, not only due to its importance for the most consistent social, behavioral, emotional, and academic development of the person with ASD they treat (Scheuermann et al., 2003), but also due to the, many times, strong misunderstandings (diversified beliefs among them), lack of knowledge and inability of the two parties to work together in a cohesive manner (Hays, 2005). Other studies discuss collaborative treatment approaches with more parties participating in the treatment intervention process (such as parent, physician, school psychologist) underlying the importance of such collaboration, since they have seen increase on individual's academic progress, self-initiation, ability to focus, and significant control over

social behavior (Ellis et al., 2007). The existing technologies nowadays, either desktop, Web-based or mobile, are numerous; with several applications to offer synchronous and asynchronous (tele-) cooperation among the members of a dedicated care team. These efforts are lying mostly under the overarching research areas of Ubiquitous Computing and Computer Supported Cooperative Work (CSCW) (Suchman, 1989). There are numerous systems that have been developed to support collaborative, synchronous meetings, with the use of shared displays and tabletop interactions (Deitz & Leigh, 2001; Russel & Gossweiler, 2001). Other systems attempt to record information gathered from a large number of resources and people and generate models. With the provision of a wide variety of features, including collaborative discussion tools, assist an expert (or a single person) to make decisions with regards to an event (Pedersen et al., 1993) or update common databases that will regenerate new data for future processing. In the field of ASD just a few attempts have been identified that designed applications to support group of individuals making complex decisions about teaching and care of persons with special needs (Kientz et al., 2006).

Nevertheless, no systems have been identified, to the best of our knowledge, that utilize technological advancements for continuous and synchronous collaboration among a care team's members that treat individuals with ASD. A 24/7 collaboration and progression update is considered vital while treating such persons. The fact that they might be suffering from physical, cognitive, or emotional disabilities limit independence and self-care or self-instruction. In addition, given the high complexity and unexpected development of ASD disorder reactions and behaviors with regards to an employed intervention might vary from session to session and/or from care-giver to care-giver (i.e. an individual with ASD might have an X response to a particular scheduled intervention task when it is at school with the teacher and a Y response in the same task while it is at home with the parent (we assume that the semantics applied in this case are the same, i.e. how to ask the individual to perform the task). This change should be communicated among the care-team for further discussion and decision making given the abnormality of the situation).

### **3 COLLABORATION CONCEPTS FOR ASD-CENTRIC VIRTUAL CARE TEAMS**

It is an indisputable fact from the so far research in the area of ASD, the highly importance of personalized treatment for persons with ASD. The generalization of a methodological approach that could fit all cases as well as a safe diagnosis that could lead to an effective intervention with no further adaptation and/or re-adjustment throughout the whole process of treatment is out of the question, given the dynamic particularities of the disorder. Hence, efficient approaches presuppose the formulation of multidisciplinary care teams that will combine knowledge and expertise towards the application of various interventions on an individual with ASD. However, formulating such an effective care team is not an easy task. Apart from the individualistic characteristics of a person with ASD, which are pretty much defined by its user profile, other important questions need to be addressed, such as: Which will be, given the case, the members of the care team? Which will be the services that will be provided? Which is going to be the pattern of communication among them? How will they share knowledge and updates of the situation for a more fruitful and realistic decision making in each stage of the treatment? What are the needs and requirements, capabilities and preferences given the uniqueness of a situation? How the given technology can be integrated to support such an attempt in the most optimized and technically viable manner, without jeopardizing the issues of privacy and security which are of high significance given the sensitivity of the medical records and uniqueness of each individual with ASD?

It has been revealed (in the eHealth and Ambient Assisted Living (AAL) sector mostly), that the integration of all these concerns under a common dynamic collaborative technological framework, that can be acceptable, successful and competent, could be achieved with the employment of Virtual Care Teams (VCT) (Georgiadis et al., 2010). Collaboration and virtual teams, abstractly, refer to the notion that a team of professionals decides to collaborate over the internet and thus create a virtual team that eliminates the need of physical presence (Pistillides et al., 2007). During the last few years there has been an increasing volume of literature on virtual organizations and virtual teams. This body of

research generally agrees that virtual teams consist of a collection of geographically dispersed individuals who work on a joint project or common tasks and communicate electronically. For example, Lipnack and Stamps (2000) define a virtual team as “a group of people who interact through inter-dependent tasks guided by a common purpose” that “works across space, time and organizational boundaries with links strengthened by webs of communication technologies”. The main benefit is that in a virtual team you can do what you can’t do alone. The challenge of our time is to learn to work in virtual teams and networks while retaining the benefits of earlier forms. In time, virtual teams will become the natural way to work. Since many virtual teams do occasionally meet physically on predefined time intervals, they find themselves in the conventional face-to-face setting. It is generally agreed that a good virtual team is, in a way, a good team.

Adapting the term into the context, needs and requirements of the ASD domain, we are suggesting the notion of *ASD Virtual Care Teams (ASD-VCT)*, that are focusing on treatment objectives for a person with ASD and consisted of members coming mainly from the three more important contextual-fields for such a person, the family, school and community. It is interesting to note that the physical distance among these team members define the urgency of the collaboration and the need for dynamicity. Indeed, virtual teams have been presented in the research literature as a communication intensive and a computer-mediated linked type of group. Electronic data interchange, computer-supported cooperative work, group support systems, as well as email, videoconferencing and teleconferencing facilities, to name but a few, enable people based in different locations to communicate and coordinate their actions with great speed and effectiveness (Samaras et al., 2005).

At this point, a fundamental issue that has to be identified is the requirements of such an ASD-centric CSCTE. Due to the peculiarity of the ASD domain, the arising contextual concepts and constraints infer to a specialized approach based on which the appropriate services will be devised for covering the needs of an ASD-VCT. Therefore, such an ASD-centric CSCTE should adhere to: (a) Availability awareness, (b) expandability, (c) easy information sharing, (d) flexible messaging methods, (e) availability (f) confidentiality, and (g) security. It has to be mentioned, that most of these requirements/characteristics have been positively evaluated in the eHealth sector (i.e. home care treatment for patients with cancer (Pitsillides et al., 2005)), and could be considered as motivating beneficial factors to be applied in the ASD sector.

#### **4 A PROPOSED ASD-CENTRIC COMPUTER SUPPORTED COLLABORATIVE TREATMENT ENVIRONMENT/MODEL**

In this section, we will propose and analyze an ASD-centric CSCTE/model that supports VCTs around individuals with ASD taking into consideration all the above mentioned needs, characteristics, and constraints. Main objective is to comprehensively identify a number of services that could be successfully communicated within and between a specific ASD-centric CSCTE on a continuous and consistent manner for maximizing, among others, communication efficiency and decision making in terms of time and accuracy. An optimized schema representation (considering the peculiarities driven by the dynamicity and abnormal proliferation of an ASD environment) is depicted in Figure 1. The particular model has been produced, having also investigated the real user needs that are referring to an ASD-centric social community level, as well as the innovative cost-effective technologies which integrate personalized socialization services.

As mentioned above, individuals with ASD are surrounded by numerous multidisciplinary parties (in terms of their treatment role) that are involved in its treatment (i.e. family, teacher, therapist, psychologist, social worker, etc.). These persons formulate VCTs that work together in favor of the person with ASD, sharing knowledge, effort and experience. In many occasions these persons can participate in other teams; of many individuals with ASD not always under the same role. Our model supports ASD-VCTs around an individual with ASD that are consisted of Users having a specific Role, taking always into consideration the individual’s Profile (see section below for an instance of an individual’s with ASD profile). These VCT members (Users) are collaborating in two levels in order to be more efficient and proactive. The first level is between users collaboration (i.e. one to one

communication for simple problem solving), while the second one is between VCTs collaboration (i.e. communication with multiple users in order to solve more complex problems).

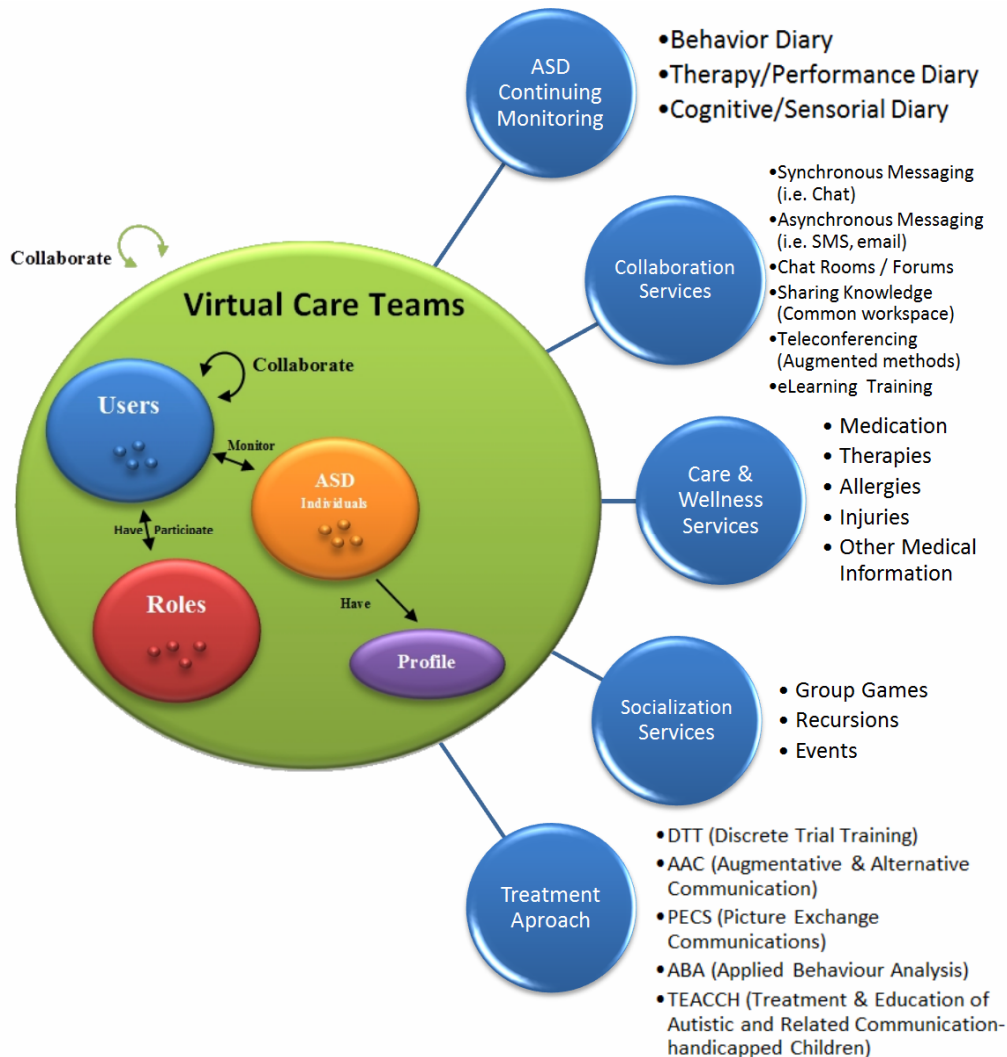


Figure 1. ASD-Centric Computer Supported Collaborative Treatment Environment

After an extensive analysis of cases and scenarios on individuals with ASD and their contextual social and communication environment that are living in, we came up with a set of services that with the utilization of the pre-mentioned notions of collaboration (see previous section), we manage to provide an enhanced QoS (Quality of Service). These services can be classified under five main categories: i) ASD Continuing Monitoring, ii) Collaboration Services, iii) Care & Wellness Services, iv) Socialization Services and v) Intervention Treatment Approach; which are briefly discussed below:

- **ASD Continuing Monitoring.** Under this category, we include services that keep track (monitor) individuals' with ASD status, performance, mood, etc. Such services are the Behavior Diary (records i.e. problematic behavior, like aggressive attacks on themselves or others, self-stimulation movements, etc.), the Therapy/Performance Diary (records progression data of the applied treatments (i.e. ABA)) and the Cognitive/Sensorial Diary (records individual's progression data with regards to perception, cognitive, emotional, and learning abilities). Users log in the system and through the use of simple interfaces, they enter information with regards to person's with ASD mood, performance, etc. on a daily basis. Other users can share this information through multiple representations (e.g. graphs or charts).
- **Collaboration Services.** In this category we encapsulate all services that support collaboration at all levels. Such services are Synchronous Messaging (i.e. instant messaging, etc.), Asynchronous



Messaging (i.e. SMS, email, fax, etc.), Chat Rooms, Forums, Common/Shared Workspace and Teleconferencing (i.e. Skype, Tango, etc.), and eLearning (i.e. for the training of parents and users that might not have the knowledge for some particular issues regarding ASD, given the multidisciplinary of the teams. Through a Web-based component a continuous update of content could be achieved increasing the acquisition learning levels).

- *Care & Wellness Services.* Care & Wellness services include services that manage medical information. This medical information includes Medication, Therapies, Allergies, Injuries and any other medical information that is needed to be disseminated throughout the VCT's members.
- *Socialization Services.* Individuals with ASD primarily have socialization problems, thus all involving parties tend to focus on socialization activities and exercises. Such activities include Group Games, Recursions and any other type of Events (i.e. spectators in sport games, concerts, etc.).
- *Intervention Treatment Approach.* In previous sections we have mentioned that various treatments can be adopted and combined for an individual with ASD based on the diagnosis that has been applied. Such treatment interventions could be Discrete Trial Training (DTT), Applied Behavior Analysis (ABA), Picture Exchange Communication (PECS), etc. Under this category we include services that support these treatments, such as shared verification mechanisms for learning progress, production of graphical results with regards to the identification of person's with ASD learning status and/or social involvement, dynamic messaging for ensuring continuous monitoring and error handling of treatment scheduling and/or abnormal behaviors/reactions, etc.

Even though a deep technological analysis and discussion that support this ASD-centric CSCTE would be beyond the scope of this paper, it is considered essential for the flow of understanding mostly, to briefly refer to the main concepts that constitute such a technological framework. Main scope of this environment for ASD-centric service development, is the provision of knowledge and guidelines in the form of service lifecycle models, and the identification of characteristics that support the provision of secure services for individuals with ASD. Such an environment should be built on technologies that facilitate service components integration and standardization for enhancing high-level interaction within and between the users of ASD-centric VCTs. More specifically, should adhere on standard technologies (i.e. XML), reuse and tailor dedicated safety and security components based on state-of-the-art security mechanisms for secure communication (based on internationally accepted ASD standards and policies), storage, and access control. The evaluation of the ASD-centric CSCTE will be twofold: framework/model evaluation and platform/system evaluation. Both of these case evaluations will be addressed by the utilization of proof-of-concept-application (POCA), which will be based on post-mortem analysis after each service/component development phase to improve system robustness and acceptability, as well as on structured interviews and questionnaires to identify usability and satisfaction levels. Main evaluation metrics will involve: Attitudes towards collaboration, assessment of knowledge about autism among the involved parties, assessment of confidence levels with regards to the proposed collaborative working environment, accuracy and time estimation of decision making process, etc.

## **5 A REAL LIFE CASE SCENARIO: DADO**

In this section we will present a real life scenario of an individual with ASD. We will elaborate on an instance of the intervention treatment approach that has been decided to be followed based on its initial diagnosis with the use of the proposed ASD-centric CSCTE and the formulation of the dedicated VCT around it. It has to be mentioned that, for ethical and confidentiality issues, the name, age and/or any other characteristics that could reveal the real identity of this person have been altered, without though deteriorating the validity of the case.

### **5.1 Dado's Short Profile Description**

Dado is a 3-year old boy who was diagnosed with a Pervasive Developmental Disorder with some autistic behaviors, with good cognitive abilities. Typical Dado's behaviors include: Avoid eye contact; turn on/off computer, cell phone and any electronic devices; open/close drawers; climbing on car top.

Parents were unable to change Dado's behaviors and to communicate with him, with great frustration of the child and his family. The child experienced the regressive autism form documented in literature, after 13 months, after a very high fever, starting to lose acquired abilities (he already pointed, pronounced some words, had eye contact, experienced social interaction, etc.) The exact diagnosis arrived only after 1 year when social, speech and communication were totally degraded and the child had become not verbal. Doctors evaluated the clinical aspects while the speech, language, and communication assessments were carried out by a psychologist specialized in autism evaluations using ad-hoc test and rate scales (Vineland Adaptive Behaviour Scales, Psychoeducational Profile (PEP 3) for the functional evaluation, etc.)

## **5.2 Dado's Intervention Approach and VCT**

Following the several failed attempts to teach the child, the mother (a pedagogist and a special needs children teacher) decided to apply ABA programs, asking support from an ABA consultant. The ABA supervisor/consultant analyzed the child's behavior, making probes (assessments) verified the child's level of skills and established the appropriate programs to make child evolve into single target skills. ABA therapy is based on DTT and AAC (see Figure 1). DTT is the primary teaching method for a number of the behaviorally-based interventions used in teaching children with autism. AAC is a technique that by increasing the user's perception provides an alternative method for communicating (for instance pictures, graphic or speech synthesis), and thus is used in treating learning disabilities and neurological pathologies. ABA teaching is centred on learning programs: matching, receptive and expressive. The learning progresses program by program on articles of common categories such as colours, shapes, numbers, letters, vehicles, animals, and on daily routines such as toilet training, brushing teeth, dressing, etc. To avoid individual's confusion, only one article is in acquisition in a specific program each time. As the level of difficulty goes higher the complexity of the trials application increases (according to DTT), i.e. mass trial, mass trial with 1 (and 2) neutral distracter, mass trial with 1 (and 2) distracter, extended trials (executed with different therapists), random rotations. The therapist sets up the table with the trial stimuli, i.e. cards/objects, and provide the instruction (discriminative stimulus), i.e. "match", "give me" or others, to the child (verbally and/or word). To avoid errors the child is initially driven by the therapist's prompts, that are gradually fade away, to bring the child at the stage that is able to operate independently and acquire the skill. The reinforcement (videogame, food, or something particularly interesting for the child) is provided when the trial is successful and independently executed, to maximize the probability that will be repeated in the future. Dado started with the first basic educational ABA programs, aiming at providing the child with basic skill for allowing smooth insertion at school. The first fundamental observation of Dado was that there was no learning since there were self-stimulatory movements. So, the first intervention focused only on child's behavior. The initial sessions lasted around 15 minutes (within 2 weeks), to reach 25 to 30 minutes (2 weeks later), to further reach 1 hour and a half in the second month. The session time gradually increased as gradually increased the child's ability to sit down and concentrate in a functional manner. The objective was for the child to reach in adequate levels of collaboration in all the ABA therapy phases; from the discriminative stimulus provided by the therapist to the reinforcement phase after the child executed the trial. It has to be stressed emphasis upon the necessity of the situation (treatment process) to be clear and unambiguous, in order for a communication channel to be established/modeled. The Dado's VCT include: 1 supervisor/consultant ABA therapist, 1 senior ABA tutor/therapist (who updates the supervisor), 5 ABA tutors/therapists, 2 Parents, Others child caregivers (relatives, baby sitter).

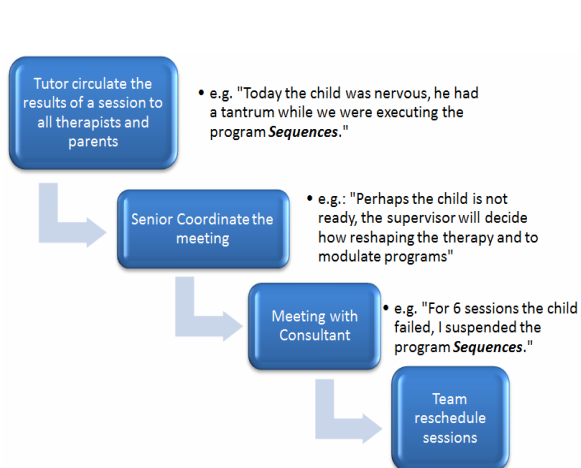
## **5.3 A Dado's Typical Treatment Day**

A typical day for Dado, it would include the following schedule:

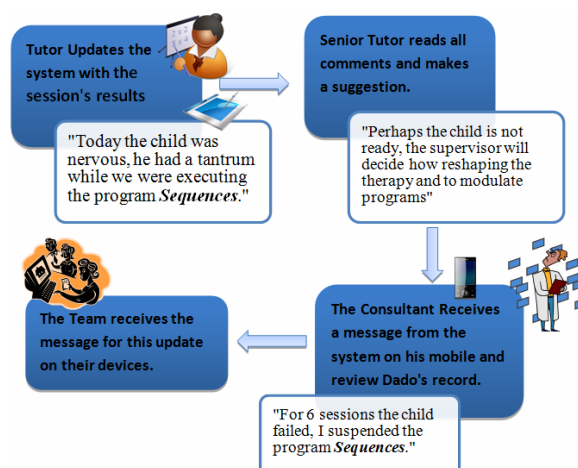
1. Tutors carry out sessions according to Dado's schedule and record trials in a paper form: Program, article, prompt (type, %), trial (n., level, outcome, reinforcement), comments.
2. Later, tutors participate (with all therapists and parents) to staff meeting, coordinated by the senior tutor.

3. Therapists generalize the ABA learning progress and also adjust the schedule according to the meeting results.
4. Later, the whole therapy team meets the consultant in order to verify the coherence between the therapists' teaching and for analysing potential problems as well as deciding a strategy to follow to fade them away.
5. The consultant makes child assessment and decides how to go ahead with ABA programs (for instance if new programs will be implemented, how to change unsuccessful programs, etc.).
6. Finally, all this information is recorded in a paper form and circulated to all team members.

In *Figure 2* we demonstrate an instance of Dado's typical treatment day. In this instance, after the treatment session, the tutor meets with Dado's parents and care team (other therapists) in order to circulate the findings (these meetings are always coordinated by Dado's senior tutor). The tutor noticed that there was a change on Dado's behavior while he was executing a specific program called *Months* (i.e., Jan, Feb, etc.) that is an article of the program *Sequences*. The senior tutor gathers the findings from all sessions and organizes a meeting with a consultant. After a consolidation with all tutors, the consultant decides to suspend the program *Sequences*. Finally, the team members are notified about this change and reschedule their session appropriately.



*Figure 2. A Dado's Typical Treatment Day Scenario*



*Figure 3. A Dado's Typical Treatment Day Scenario using ASD-centric CSCTE*

As we can observe from the traditional treatment setting above, there are some important communication limitations which may lead to particular inefficiencies, with regards to i.e. timely information sharing, cost savings and comprehensive decision making. These weaknesses are: (i) support of care provision anytime and anyplace, (ii) limited communication schemas due to the fact that all communication and exchange of data is face-to-face, (iii) limited continuity of care, (iv) limited collection of statistical data and (v) lack of cross-organizational collaboration support of specialists. The satisfaction of these drawbacks, have also initially motivated us for the development of the proposed ASD-centric CSCTE, aiming to the improvement of the quality of service provision.

In *Figure 3* we illustrate the abovementioned scenario using the proposed ASD-CSCTE model. For each child with ASD we formulate a VCT by assigning users with roles that will participate in that specific team. All team members are equipped with mobile devices (i.e. iPhones, iPads, Android phones, HTC windows mobile enabled, laptops, etc.). VCT members can access and update all information about their caring individual easily from anywhere and anytime (24/7) with the utilization of mobile technologies (i.e. GPRS, 3G, wifi, etc.), depending on their authentication rights. In our case, the tutor, instead of having a meeting with all team members, sends an online report with the Dado's session results. All other team members, including the senior tutor, can view instantly the

results. The senior tutor reviews the given results along with all the other results (from other tutors and sessions) concerning Dado. The derived consensus with regards to the case progression is better supported and documented. We notice that by utilizing the messaging service of the proposed treatment environment, we save valuable time and effort. Similarly, the consultant is getting the message and accesses the child's file from his mobile device. Having at hand all information, he decides a change on the Dado's program. By finalizing the change, all involved care team members, are alerted automatically by the system through messaging technologies such as SMS. The particular approach highly demonstrates the feasibility potential cost effectiveness and decision making by the utilization of the proposed ASD-centric CSCTE.

## **6 CONCLUSION AND FUTURE WORK**

In this paper we proposed an ASD-centric Computer Supported Collaborative Treatment Environment/model, which aims to provide continuous treatment through an enhanced synergy of care team parties assigned around an individual with ASD. It has been recognized that early personalized treatment interventions, accurate exchange of information and prompt delivery of services to such persons increase their intellectual and social abilities and make them feel more comfortable and adapted to their contextual environment. As individuals with ASD have many unique and divergent needs, professionals from diverse and relevant areas of expertise must work together to optimize the outcomes for these persons and their families. With an integrated collaborative treatment approach, practical and informed decision making is a derived result from the inclusion of all parties in the treatment process which is consistently addressing the needs and requirements of individuals with ASD. In this respect, we strongly believe that the employment of Virtual Care Teams in a collaborative care environment can significantly enhance the main strategies used by all care parties that are emphasized on collaboration in the sharing of information for data-based decisions regarding diagnosis, treatment planning, and intervention and ongoing monitoring in order to meet the medical and educational needs of persons with ASD. The latter conceptualization benefits are also grounded from the ongoing positive evaluation of VCTs in the eHealth sector. Based on an extensive research on the individualistic and contextual characteristics of persons with ASD, literature review and interviews with specialists we have proposed a set of services that utilize the basic notions of CSCW environments and are classified under five main categories: i) ASD Continuing Monitoring, ii) Collaboration Services, iii) Care & Wellness Services, iv) Socialization Services and v) Intervention Treatment Approach. The particular services are expressing the main outputs of our proposed ASD-centric CSCTE and provide an added value to the communication among care parties, monitoring and error handling, decision making and social inclusion, improving the quality of life of the person with ASD.

Expected limitations on the implementation of the proposed model include not only the common problems of adopting information and communication collaborative technologies in the dynamic ASD environment (i.e. reorganization working process, phobia of technology, lack of trust, limited budget), but also long delays in research funding continuation, mismatch between users' high expectations and inability of the technical team to enlighten them with regards to the complexity and time required for such an endeavor, as well as difficulties on defining particular dynamic workflows given the multidisciplinary of the care team's members – in many cases present different viewpoints, beliefs and attitudes towards a unified action plan. Next steps of this research include the design and implementation of the system's architecture, based on the proposed model, which will embrace the latest technological advancements (desktop, Web based, and wireless/mobile) and will ensure openness, interoperability, and integration of its components over a secure dynamic workflow. Further evaluation of the architecture's benefits, including a cost benefit analysis, and a formal study of interactions (on a system level), between VCT's members will be undertaken with a view to the provision of adaptability processes in the virtual team interactions and work flow dynamics.

## References

- American Academy of Pediatrics, Committee on Children with Disabilities. (2001). Technical report: The pediatrician's role in the diagnosis and management of autistic spectrum disorders in children. *Pediatrics*, 107, e85.
- American Psychiatric Association. (2000). *DSM-IV-TR. Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition. Text Revision.*
- Anderson, S.R. and Romanczyk, R.G. (1999). Early Intervention for Young Children with Autism: Continuum-Based Behavioral Models. *The Journal of The Association for Persons with Severe Handicaps* 24, 3 (1999), 162-173.
- Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E. and Rutter, M. (1995). Autism as a strongly genetic disorder: Evidence from British twin study. *Journal of Psychological Medicine*, Cambridge University Press, 25(1), pp. 63-77.
- Bryson S.E., Rogers S.J. and Fombonne E. (2003). Autism Spectrum Disorders: Early Detection, Intervention, Education, and Psychopharmacological Management. *Canadian Journal of Psychiatry*, Vol 48, No 8.
- Charman T. and Baird G. (2002). Practitioner Review: Diagnosis of Autism Spectrum Disorder in 2- and 3-year-old Children. *Journal of Child Psychology and Psychiatry* 43(3), pp. 289-305.
- Christodoulou E., Samaras G., Polydorou E., Tsiourti C., Belk M., Building Virtual Care Communities Supporting Elderly Socialization and Independent Living by integrating mobile wireless ICT based services, Conference Proceedings of Med-e-Tel 2010, Luxemburg 14-16 April 2010
- Committee on Children with Disabilities, American Academy of Pediatrics. (1994). Screening infants and young children for developmental disabilities. *Pediatrics*, 93, 863-865.
- Corsello, C.M. (2005). Early intervention in autism. *Infants & Young Children*, 18(2), pp. 74-85, Lippincott Williams & Wilkins, Inc.
- Deitz, P. and Leigh D. (2001). DiamondTouch: a multi-user touch technology. In 14th annual ACM symposium on User interface software and technology (UIST '01).
- Drotar, D., Palermo, T. and Barry, C. (2004). Collaboration with schools: Models and methods in pediatric psychology and pediatrics. In R.T. Brown (Ed.), *Handbook of pediatric psychology in school settings*, pp. 21-36, Mahwah, NJ: Erlbaum.
- Ellis C.R., Lutz R.E. and Schaefer G.B. (2007). Physician Collaboration involving students with autism spectrum disorders. *Psychology in the Schools*, Wiley Periodicals, Inc., DOI: 10.1002/pits.20262, Vol. 44(7).
- Filipek, P.A., Accardo, P.J., Ashwal, S., Baranek, G.T., Cook, E.H., Dawson, G.,... Volkmar, F.R. (2000). Practice parameter: Screening and diagnosis of autism. Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55, 468-479.
- Georgiadis D., Christodoulou E., and Samaras G. (2007). Dynamic Workflows for Wireless Collaboration in eHealth Domain, eCSCW 2007, Limerick, Ireland, 24-28 September.
- Georgiadis D., Germanakos P., Mourlas C., Samaras G., and Christodoulou E. (2010). Dynamic Business Processes and Virtual Communities in Wireless eHealth Environments. A chapter to appear in: *Ubiquitous Health and Medical Informatics: the Ubiquity 2.0 Trend and Beyond*, S. Mohammed & J. Fiaidhi (Eds.), IGI Global, Hershey, USA, 2010. (ISBN: 978-1-61520-777-0)
- Hays, A. (2005). Parent-Teacher Collaboration for Students with Autism Spectrum Disorders: The Role of Teacher Training. Honors Projects, Paper 9.
- Howlin, P. (2008). Identifying effective interventions for young children with autism spectrum disorders. *Journal of Intellectual Disability Research*, 52(10), 817.
- Kerrell, H. (2001). Service evaluation of an autism diagnostic clinic for children. *Nursing Standard*, 15, 33-37.
- Kientz A.J., Hayes G.R, Abowd G.D. and Grinter R.E. (2006). From the War Room to the Living Room: Decision Support for Home-based Therapy Teams. CSCW'06, November 4-8.
- Koegel L., Carter C. and Koegel R. (2003). Teaching children with autism self-initiations as a pivotal response. *Topics in Language Disorders*. 23. 134--145.
- Koegel, R.L., Koegel L.K., Frea W.D. and Smith A.E. (1995). Emerging interventions for children with autism: Longitudinal and lifestyle applications. In *Teaching Children With Autism: Strategies*

- for Initiating Positive Interactions and Improving Learning Opportunities, Edited by Koegel RL, Koegel LK. Baltimore: Paul H. Brookes Publishing Co; 1995:1-15.
- Landa, R. J., Holman, K. C. and Garrett-Mayer, E. (2007). Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of General Psychiatry*, 64(7), 853-864.
- Lindblad, T. (1996). Language and communication programming and intervention for children with autism and other related pervasive developmental disorders.
- Lipnack J. and Stamps J. (2000). *VIRTUAL TEAMS: People Working Across Boundaries with Technology*. Second Edition, Published by John Wiley & Sons, NY.
- Lord, C., Risi, S., DiLavore, P.S., Shulman, C., Thurm, A. and Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 63, 694–701.
- Moore, D. (1998). Computers and people with autism/Asperger syndrome. *Communication (the magazine of The National Autistic Society)*, pp. 20–21.
- National Research Council. (2001). *Educating children with autism (Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education)*. Washington, DC: National Academy Press.
- Pedersen, E.R., McCall, K., Moran, T.P. and Halasz, F.G. (1993). Tivoli: An Electronic Whiteboard for Informal Workgroup Meetings. In *Proceedings of INTERCHI '93*. ACM Press, pp. 391-398.
- Pinto-Martin, J., Weissman, A. and Mandell, D. (2009). Screening and Detection of ASD: The State of the Science in Research and Practice. Chapter VI, *Trends in Autism Research*, Editor: O.T.Ryaskin, Nova Science Publishers, Inc.
- Pitsillides A., Samaras G., Georgiadis D., Andreou P., Christodoulou E. and Pitsillides B. (2007). Tele-homecare supported by the DITIS collaborative platform. *IST Africa*, 09 - 11 May 2007, Maputo, Mozambique, Africa.
- Pitsillides A., Pitsillides B., Samaras G., Dikaiakos M., Christodoulou E., Andreou P., and Georgiades D. (2005). A Collaborative Virtual Medical Team for Home Healthcare of Cancer Patients, Book Chapter, *M-Health: Emerging Mobile Health Systems*, (R. H. Istepanian, S. Laxminarayan, C. S. Pattichis, Editors), Kluwer Academic/Plenum Publishers, pp. 247-266, 2005. (ISBN: 978-0-3872-6558-2)
- Power, T., DuPaul, G.J., Shapiro, E.S. and Kazak, A.E. (2003). *Promoting children's health: Integrating school, family, and community*. New York: Guilford Press.
- Rogers, S.J. and Vismara, L. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 8-38.
- Ruble, L.A.A. and Akshoomof, N. (2010). *Autism Spectrum Disorders: Intervention Options for Parents and Educators*. Communiqué Handout: January/February 2010, Volume 38, Number 5
- Russell, D. and R. (2001). Gossweiler. On the Design of Personal & Communal Large Information Scale Appliances. In *Proceedings of the 3rd international conference on Ubiquitous Computing*, pp. 354-361.
- Samaras, G., Georgiades, D. and Pitsillides, A. (2005). Computational and Wireless Modeling for Collaborative Virtual Medical Teams, Book Chapter, *M-Health: Emerging Mobile Health Systems*, (R. H. Istepanian, S. Laxminarayan, C. S. Pattichis, Editors), Kluwer Academic/Plenum Publishers, pp. 107-132.
- Shellenberger, S. and Couch, K.W. (1984). The school psychologist's pivotal role in promoting the health and well-being of children. *School Psychology Review*, 13, 211–215.
- Scheuermann, B., Webber, J., Boutot, E. A. and Goodwin, M. (2003). Problems with personnel preparation in autism spectrum disorders. *Focus on Autism & Other Developmental Disabilities*, 18(3), 197-206.
- Suchman, L. (1989) Notes on Computer Support for Cooperative Work. Working Paper WP-12, Dept. of Computer Science, University of Jyväskylä, SF-40100, Jyväskylä, Finland.
- Volkmar, F.R., Cook, E.H., Jr., Pomeroy, J., Realmuto, G. and Tanquay, P. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(12 Suppl.), 32S–54S.
- Young J., Corea C., Kimani J. and Mandell D. (2010). *Autism Spectrum Disorders (ASD) Services. Final Report on Environmental Scan*, IMPAQ International, LLC.