EMBRACING COMPLEXITY: USING TECHNOLOGY TO DEVELOP A LIFE-LONG LEARNING MODEL FOR NON-WORKING TIME IN THE INTERDEPENDENT HOMES FOR ADULTS WITH AUTISM SPECTRUM DISORDERS

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ABSTRACT

The purpose of this study was to employ complexity theory as a theoretical framework and technology to facilitate the development of a life-long learning model for non-working time in the interdependent homes for adults with Autism Spectrum Disorders (ASD). A "Shining Star Sustainable Action Project" of the ROC Foundation for Autistic Children and Adults in Taiwan (FACT) was selected as the research target, and the staff of the FACT, the medical team of the Hualian Yuli Veteran Hospital, adults with autism and their families were interviewed, observed and analyzed to develop this model during four short-stays of the project from July 2009 to December 2010. Participant field observation and informal conversations were employed and qualitative data were analyzed by using the constant comparison method through application of QSR Nvivo 9. The results showed that dynamic interaction, mutual adaptation, self-organization and co-evolution are four key elements for developing a viable life-long learning model for non-working time in the interdependent homes for adults with ASD to adapt to the impact of an aging society, to improve the quality of medical services, and to enhance the quality of life for the medical teams, patients and their families. The present study also found that the model help medical teams to avoid burnout by learning leisure skills and relaxation techniques, ways to release stress and how to enhance life-long learning for themselves and caregivers/patients' families.

Keywords: interdependent home, autism, complexity, quality of life

INTRODUCTION

Raising adults with Autism Spectrum Disorders (ASD) can be stressful and confers exceptional challenges on caregivers and their family members (Baker, Hartley, Seltzer, Floyd, Greenberg & Orsmond, 2011; Smith, Jinkuk, Seltzer, Greenberg, Almeida & Biship, 2010). The challenges are difficult to overcome because the nature of core symptoms of ASD, which include impairments in communication and reciprocal social interaction, and the presences of restricted and repetitive behaviors and interests (American Psychiatric Association, 2000). Therefore, developing long-term care services for adults with ASD is one of the most crucial issues for the autism community. Chiang, Lee, Frey, & McCormick (2004) used a videogame-based intervention to improve the quality of friendship for individuals with ASD and found positive impacts on several components of friendship quality, peer recognition through physical competence, and social expectations among participants. Related research also echoes these findings of the study and points out that using technology has the potential to enhance the quality of learning motivation for individuals with ASD (Narkon, Wells & Segal, 2011).

Non-Working Time in the Interdependent Homes

Lu, Chiang and Wang (2008) first stated that interdependent homes could create a happier and friendlier environment for people with intellectual disabilities. The concept of interdependent homes involves a "mixed" care system between professional/organizational facilities and home-based cares. Groups of parents who have children with ASD are united to set up home-based care facilities and take turns being the parents of the interdependent homes. In order to insure quality of care, professionals from health care, education, and social work are retained to provide professional services to support the interdependent homes on a regular basis. However, the study points out that there remains a lack of human resources at the interdependent homes, particularly during non-working times and days (e.g. after-work, days-off, weekends, holidays, summer and winter vacations). Because adults with ASD have diverse interests and disabilities, it is a complex challenge to construct a life-long learning environment in the interdependent homes. McConnell, Lekan-Rutledge, Nevidjon & Anderson (2004) stipulated that complexity theory is valuable for long-term care settings to adapt to complex situations because the theory has been pervasively applied in numerous types of research and practices to adapt to multiple environmental changes and multidisciplinary collaboration in both natural and social sciences. As a result, the purpose of the current study represented an attempt to employ complexity theory as a theoretical framework and technology to facilitate the development of a life-long learning model for non-working time in the interdependent homes for adults with ASD.

METHODOLOGY

FACT Short Stays

This study cooperated with the 5-year "Shining Star Sustainable Action Project" of the ROC Foundation for Autistic Children and Adults in Taiwan (FACT). The staff of the FACT and the medical team of the Hualian Yuli Veteran Hospital (HYVH) were recruited as the service team for this project. The goals of the FACT Project are as follows: (1) initiative collaboration between the FACT and HYVH; (2) designing an autism-centered long-term care program with the concept of home rebuilding; and, (3) developing a multidisciplinary holistic care model by combining medicine, nursing, psychology and counseling, social work, and occupational therapy. Major activities in the FACT project were described in Figure 1. A collaborative memorandum of understanding (MOU) between the FACT and HYVH was initiated and signed on July 20, 2006 and the second MOU was signed on November 25, 2008. The project began to execute the first short stay during July 20 to July 31, 2009. According to the health conditions, availability and appropriateness screenings of participants, the other 3 short stays were held during October 19 to October 30 in 2009, May 3 to May 15 and November 8 to December 31 in 2010.

Collaborative Workshops
Site Visiting
Signing MOU
Summer camp
Parents meetings

Figure 1: Developing Processes of "Shining Star Sustainable Action Project"

Participants

The medical and support teams, adults with autism and their families were interviewed, observed and analyzed to develop this life-long learning model for non-working time in the interdependent homes during 4 short stays from July 2009 to December 2010. The medical team members included the superintendent and a psychiatric doctor, one head nurse, two clinic counselors, one social worker, and two occupational therapists from the HYVH. The support team members are two teachers and three social workers from the FACT. The first stays recruited 9 adults with autism and some of their parents to participate. With screening process, the number of participants decreased to three individuals at the forth stay (Table 1). All participants in this project were interviewed and observed when they were available during those short stays.

Table 1: Demographic information of Participants with ASD

Case No.	Gender	Age	Diagnosis*	Education**	Short Stay Participation
1	Male	29	SASD+ID	SSHS	1, 2, 3, 4
2	Male	31	SASD+ID	SSHS	1, 2, 3, 4
3	Male	34	MASD+ID	SSHS	2,3,4
4	Male	24	MASD	SVSHS	1,2
5	Male	28	SASD+ID	SSHS	1,2,3
6	Male	20	MASD+ID	SSHS	1,2,3
7	Male	19	SASD+ID	SSHS	1,2
8	Female	19	PASD+HD+EP	SSHS	1
9	Female	23	ASD+EP	SVSHS	1,2

*Note 1: SASD: Severe ASD; ID: Intellectual Disabilities; MASD: Moderate ASD; PASD: Profound ASD; HD: Hearing Disability; EP: Epilepsy
**Note 2: SSHS: Special Senior High School; SVSHS: Special Vocational Senior High School

Data Collection and Analysis

Two qualitative research methods, participant field observation and informal conversations, were used to collect responses and feedback as field notes from the adults with autism and their family members, the medical team members, and the support team members in this study. All data were gathered and analyzed by the primary investigator who has previous qualitative research experience and long-term working experience with autism populations. Member checking, peer debriefing and auditing are three main research procedures to enhance the trustworthiness, credibility and transferability of this qualitative study. The QSR Nvivo 9 Software Package was used in coding, sorting and generating themes of the data.

Theoretical Framework: Complexity Theory

Theories are constructed in order to explain, predict and master phenomena (e.g. relationships, events, or behavior) to make generalizations about observations and to consist of an interrelated, coherent set of ideas and models. Complexity theory has been pervasively applied in a variety of professions to adapt to multiple environmental changes and multidisciplinary collaboration in recently research (Paley, 2007). Evolved from Chaos theory and the idea of Lorenz attractor (Figure 2), complexity theory which emphasizes uncertainty and randomness constructs a non-linear dynamic system that traditional organizational theories are inability to explain and predict. In the healthcare- and education-related literatures, there is a growing attention in complexity theory and its implications. For example, there are a variety of research and professions that employ complexity theory as the theoretical framework in their studies, such as medical education (Fraser & Greenhalgh, 2001; Rees & Richards, 2004), health promotion (Wilson & Holt, 2001), shared care for patients with long-term mental illness (Byng & Jones, 2004), and healthcare management (Plsek and Wilson, 2001).

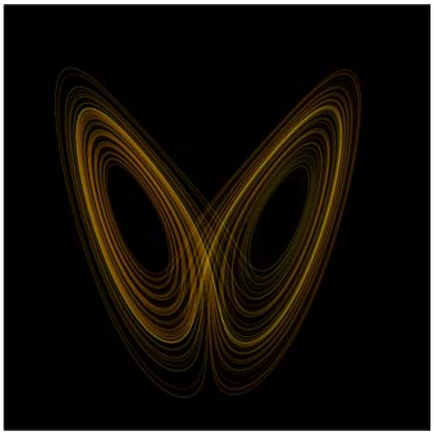


Figure 2: An icon of chaos theory - the Lorenz attractor (Source from Wiki Foundation, http://en.wikipedia.org/wiki/ File:Lorenz_attractor_yb.svg)

Complexity theory has a great strength when being used to explain the adaptability and survivability of systems that need paradoxical explanations (Grobman, 2005). The theory provides a graphical framework that outlines a complex zone with appropriate degree of agreement and certainty between simple and chaotic situations (figure 3). Since a theoretical framework of a study could provide a theory-based structure that can hold and support the conceptual foundation of a research work, it presents this complexity theory which may help to explain why the research questions under the study exists. Thus, the present study uses the theory as theoretical framework to construct a life-long learning model for non-working time in the interdependent homes for adults with ASD.

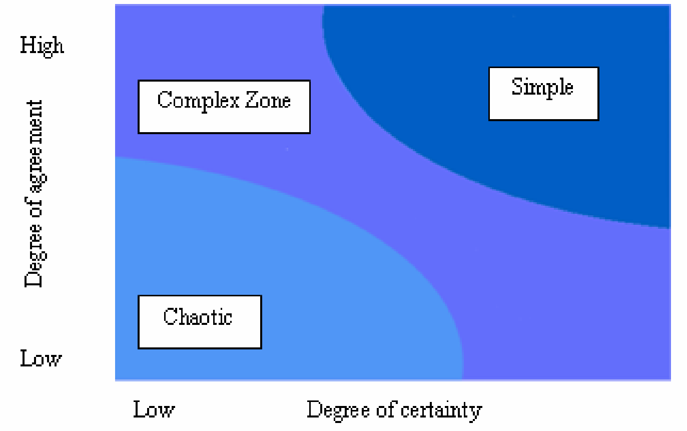


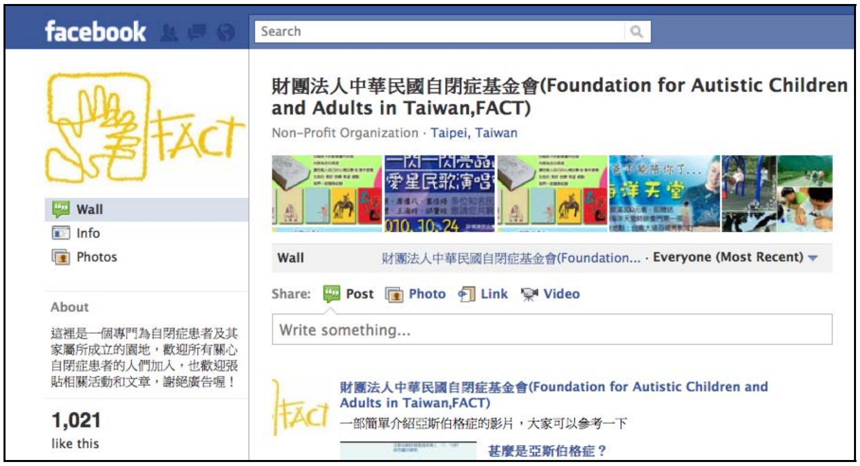
Figure 3: A graphic framework of complexity theory (Adapted from Plsek & Greenhalgh, 2001)

RESULTS & DISCUSSION

According to the results of the qualitative information, dynamic interaction, mutual adaptation, self-organization and co-evolution are identified as four key elements for developing a viable life-long learning model for non-working time in the interdependent homes for adults with ASD through technology. Those elements help not only these individuals with ASD and their families but also the medical teams and related professionals to adapt to the impact of an aging society, to improve the quality of medical services and to enhance their quality of life.

Dynamic Interaction

Dynamic interaction addresses on the importance of increasing interactions between the organizations, professionals, and adults with ASD. For example, the FACT and HYVH have to find possible solutions to develop viable human resource arrangement for non-working time in the interdependent homes since it is a home-based long-term care model for adults with ASD and their parents. Therefore, dynamic interactions are highly recommended and technology can play a crucial role to facilitate better interactions between the organizations and these family members. For example, the immediate communications via Web 2.0 technology (e.g., Facebook, Plurk, Twitter, Google+) are advised to increate the dynamic interaction. Figure 4 demonstrates that the FACT has begun to use Facebook to interact with individuals with ASD and families who have children or adults with ASD.



財團法人中華民國自閉症基金會(Foundation for Autistic Children and Adults in Taiwan,FACT)
Non-Profit Organization · Taipei, Taiwan

財團法人中華民國自閉症基金會(Foundation...

About
這裡是一個專門為自閉症患者及其家屬所成立的園地，歡迎所有關心自閉症患者的人們加入，也歡迎張貼相關活動和文章，謝絕廣告喔！

財團法人中華民國自閉症基金會(Foundation for Autistic Children and Adults in Taiwan,FACT)
一部簡單介紹亞斯伯格症的影片，大家可以參考一下
甚麼是亞斯伯格症？

Figure 4: The FACT Facebook page

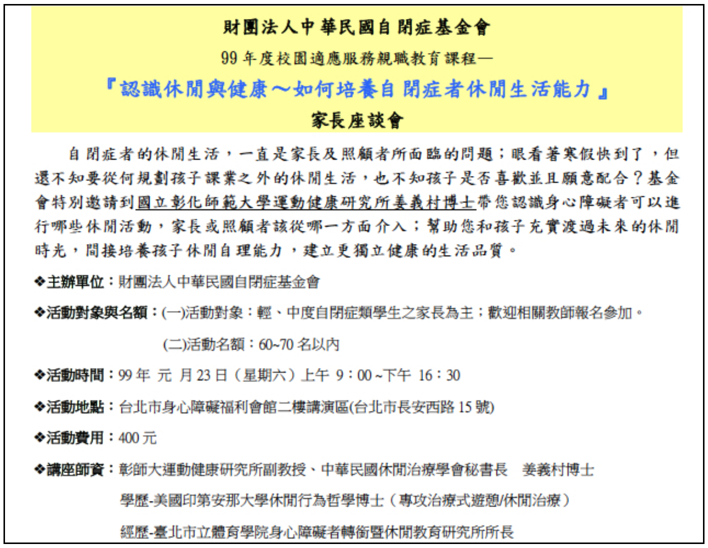
Mutual Adaptation

According to complexity theory, mutual-adaptation stipulates that developing multidisciplinary collaboration is extremely important to adults with ASD in such a diverse life-long learning environment. Traditionally, the professional, medical or support team members who provide services for adults with ASD are mostly from the areas of medical, nursing, special education, physical therapy, occupational therapy and social worker professions. All of those professionals do not have academic trainings or practical experiences on facilitating leisure, recreation, sports or other life-long learning activities for non-working time in the interdependent homes. Therefore, the model suggests that mutual adaptation shall be promoted to advance technology-related and leisure-related knowledge in those helping professions. For example, higher educators in those professions are recommended to revise their curriculum and to add more technology-based (e.g., e-learning) and leisure-related courses (e.g., therapeutic recreation) in their professional preparation, practical trainings and continuing education. In this study, one occupational therapist identified her needs in leisure-related continuing education and said,

> *"It is a pity that I did not have a chance to attend leisure education workshops two years ago. I think that leisure and recreation activities are definitely needed for those adults with ASD if they plan to stay here for a long time. During weekends and holidays, I always think what leisure activities that I can teach if I am on duty. Unfortunately, this is one of my limitations because I do not have any previous training on providing therapeutic recreation sessions or prescriptive leisure activities for those adults with ASD."*

Self-Organization

Self-organization strongly recommends that service providers (e.g. FACT and HYVH) and parents support groups shall start to advocate and develop non-working time leisure and recreation programs for individuals with ASD. The concept of self-organization not only provides leisure and recreation for non-working time for adults with ASD, but also gives a window for the medical team members to avoid burnout by learning leisure skills and relaxation and perceiving fun and enjoyment during their service delivery processes. Therefore, continuing leisure education programs are identified as an important component for their self-organizations. Figure 5 shows that the FACT began to hold a leisure education workshop for professionals who were interested in teaching leisure education and parents who have children with ASD on January 23, 2010.



財團法人中華民國自閉症基金會

99 年度校園適應服務親職教育課程—

『認識休閒與健康～如何培養自閉症者休閒生活能力』

家長座談會

自閉症者的休閒生活，一直是家長及照顧者所面臨的問題；眼看著寒假快到了，但還不知要從何規劃孩子課業之外的休閒生活，也不知孩子是否喜歡並且願意配合？基金會特別邀請到國立彰化師範大學運動健康研究所姜義村博士帶您認識身心障礙者可以進行哪些休閒活動，家長或照顧者該從哪一方面介入；幫助您和孩子充實渡過未來的休閒時光，間接培養孩子休閒自理能力，建立更獨立健康的生活品質。

❖**主辦單位**：財團法人中華民國自閉症基金會

❖**活動對象與名額**：(一)活動對象：輕、中度自閉症類學生之家長為主；歡迎相關教師報名參加。
(二)活動名額：60~70 名以內

❖**活動時間**：99 年 元 月 23 日（星期六）上午 9：00 ~下午 16：30

❖**活動地點**：台北市身心障礙福利會館二樓講演區(台北市長安西路 15 號)

❖**活動費用**：400 元

❖**講座師資**：彰師大運動健康研究所副教授、中華民國休閒治療學會秘書長　姜義村博士
學歷-美國印第安那大學休閒行為哲學博士（專攻治療式遊憩/休閒治療）
經歷-臺北市立體育學院身心障礙者轉銜暨休閒教育研究所所長

Figure 5: The FACT Leisure Education Workshop Flyer

Co-Evolution

The study found that both the FACT and HYVH have to expand their concepts on their service spectrum for adults with ASD in this interdependent home, such as adding learning time slots (e.g., after school hour, midnight, early morning), changing learning styles (e.g., needing a great amount of multimedia to keep concentration), facilitating feedback opportunities (online electronic interaction), and increasing their learning motivation (e.g., computer attachment, video-/audio-information). This theme identified that the professional organizations have to co-evolve and improve their services and innovations on technology-based learning and leisure opportunities when there will be a lack of human resources during non-working time. For instance, the executive of the FACT expressed his opinion on providing technology-based learning and leisure opportunities for adults with ASD and stated,

> *"I believe that this approach is absolutely correct. Those adults with ASD have strong needs in continuing education in this long-term care model and in such a remote site. It is impossible to invite teachers or experts to come here every weekend; of course, we won't have enough*

> *money to do that. Therefore, I think that using technology-based learning is a very good way to do it! Additionally, if we can use this technology to teach them to make friends, have some fun and enjoyable time, that will be awesome!"*

CONCLUSIONS

The aim of this research is to develop a life-long learning model for non-working time in the interdependent homes for adults with ASD by employing complexity theory as a theoretical framework and using technology as a facilitation technique. Paley (2007) states that applying complexity theory in health care service and health related organizations is a right approach, however, it is believed that this approach is still in its embryonic state of the complexity science development. The results show that this life-long learning model builds on the theoretical base of complexity theory used to address survivability and adaptability successfully outlined four key elements to develop better services for non-working time in the interdependent homes for adults with ASD. In addition, it also assists helping professionals to prevent burnout by learning leisure skills and relaxation techniques, ways to release stress and how to have continuing leisure education opportunities for themselves and caregivers/patients' families.

Several matters arising from the research methodology may have impacted on these final results. First, this study only can gather information from four short stays and the lack of directly empirical long-term data (e.g. real interdependent homes) to support the model may be criticized due to the nature of exploratory study design. Nevertheless, the study still provides valuable contributions to stipulate possible practical solutions for non-working time and services in the interdependent homes by having solid theoretical framework support and critical literature review. Secondly, another potential challenge would question on the legitimacy of borrowing concepts of complexity theory as a metaphors from the physical and biological sciences. In order to overcome this challenge, a great number of previous studies in health-related and educational professions on complexity theory have been critically reviewed. Satisfactory in predicting solutions on multidisciplinary collaborations was found because complexity theory provides a new angle in looking at how complex environment and structures form, adapt, and change. The academic nature of the research was emphasized in this study.

ACKNOWLEDGEMENTS

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