

**STIGMA AND PROTECTIVE FACTORS: A STUDY OF
RESILIENCE AMONG YOUTH
WITH DISABILITIES**

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DECLARATION

I hereby declare that the work in this dissertation is my own except for quotations and summaries which have been duly acknowledged.

2 March 2011

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ABSTRAK

Tujuan utama kajian ini adalah untuk menghasilkan data empirikal yang dapat menunjukkan sebarang fenomena pada faktor pelindung bagi remaja berkeperluan khas dan jika ada pengaruh stigma terhadap interaksi mereka dengan faktor-faktor pelindung. Faktor pelindung adalah elemen yang terbukti penting dalam pembentukan jati diri. Rekabentuk kajian menggunakan kaedah kuantitatif dan kualitatif. Responden terdiri daripada 8 orang remaja (4 lelaki dan 4 perempuan) berkeperluan khas yang dipilih berdasarkan dua kategori iaitu kecacatan yang boleh dilihat dan yang tidak mudah dilihat. Instrumen yang digunakan adalah soal selidik jati diri dwibahasa. Instrumen asal telah dialih bahasa menggunakan kaedah penterjemahan Brislin dan faktor analisis ke atas 46 sampel pelajar telah digunakan untuk menentukan kesahan dan kebolehpercayaan instrumen. Lapan profil jati diri individu yang telah dijana dari instrumen itu telah melihatkan beberapa fenomena berkenaan faktor pelindung. Sementara itu, temubual yang dilakukan berdasarkan kaedah Strauss dan Corbin telah dapat mengesahkan dapatan skor instrumen jati diri dan menyiasat pengaruh stigma terhadap responden. Dapatan menunjukkan faktor pelindung, iaitu kawalan sendiri, pemberdayaan diri and kejelikitan komuniti adalah perkara yang lemah manakala sekolah dan sikap terhadap belajar adalah kekuatan mereka. Dapatan menunjukkan kecacatan yang boleh dilihat mempunyai pengaruh terhadap interaksi dengan faktor pelindung. Penyelidik menamakannya sebagai ruang I-E. Tidak seorang pun responden menyatakan gembira atau bersyukur kerana telah mengalami stigma. Malah kesemua responden memberi respon negatif apabila mengalami stigma. Dapatan menunjukkan perasaan sedih dan malu sebagai yang paling tinggi dialami. Lain-lain emosi ialah marah, takut dan kebimbangan sosial. Respon kelakuan terhadap stigma didapati berfungsi sebagai strategi untuk mengatasi masalah yang timbul akibat stigma. Ianya termasuk mengelak, mendapatkan pertolongan orang dewasa, melawan balik, cuba menghilangkan punca stigma, menafi, menyendiri, sengaja tidak mengendah, memikirkan perspektif pengstigma, memujuk diri sendiri dan menulis dairi. Dapatan juga menunjukkan mereka sanggup membunuh diri jika merasakan tiada lagi orang yang perihatin akan kesukaran yang dialami. Kajian ini memberi implikasi bahawa ibu bapa, penjaga, para pendidik dan ahli perubatan perlu mengetahui pengaruh negatif stigma terhadap faktor pelindung agar dapat membantu dalam proses membina jati diri remaja berkeperluan khas. Dapatan juga memberi implikasi bahawa perkembangan seksual remaja berkeperluan khas sangat penting dalam kehidupan mereka dan elemen ini perlu diambil kira sekiranya jika ingin membina jiwa yang tebal dengan jati diri. Akhir sekali, dapatan menunjukkan bahawa menjaga individu berkeperluan khas adalah tanggungjawab yang amat sukar dilaksanakan terutama untuk masa jangka panjang. Stres yang terhasil mampu menyebabkan layanan buruk terhadap individu berkeperluan khas dan perkara ini sangat kritikal. Secara keseluruhannya, dapatan kajian ini boleh digunakan sebagai sebahagian daripada sesuatu rangka atau program untuk remaja berkeperluan khas dalam usaha membina jati diri yang tinggi dan mampu bertahan pada jangka masa yang panjang dan secara berterusan.

ABSTRACT

The main aim of this study is to generate empirical data to show any common phenomena in the protective factors of youths with disabilities and if stigmatizing experiences influences subsequent interactions with protective factors. Protective factors are elements that are known through years of research to be crucial for the development and maintenance of resilience. This study is a mixed method research design. Eight respondents (4 males and 4 females) were selected based on two wide categories: visible and invisible disabilities. A bilingual 5 point Likert scale resiliency questionnaire was used on all respondents to measure the strengths of their 10 protective factors. Brislin back-translation method and factor analysis on an initial sample of 46 students was used to form the Malay version and to determine construct validity and reliability. Individual resiliency profiles were generated from this instrument which allowed for the scrutiny for common patterns while interviews guided by Strauss and Corbin's grounded theory method were carried out to validate the resiliency scores and investigate respondents' stigmatizing experiences. Triangulation of both qualitative and quantitative data resulted in the identification of several common phenomena. Findings on the protective factors, mainly self-control, empowerment and community cohesiveness are areas of challenge while school and learning are areas of strengths. The visibility of the disability was also found to have an influence on respondents' engagement with their protective factors, named by the researcher as the I-E gap. None of the respondents expressed joy or gratitude that they have been stigmatized. All expressed negative emotional responses to stigma with shame and sadness at the top of the list. Other emotions felt include anger, fear and social anxiety. Overt behavioural responses to stigma was found to function as coping strategies by the respondents with includes avoidance, getting adult help, fighting back (by themselves), try to erase stigma, denial, self-isolation, ignore, reasoning the stigmatizer's view, positive self-talk and diary writing. Findings also show that if perceived as having no more support from external sources, the disabled is capable of taking their own life. The findings in this study strongly imply that parents, caregivers, educational and medical professionals must be aware of the influence of stigma and how it negatively influence subsequent interactions with protective factors to enable them to know how to assist and guide youths with disabilities foster and maintain a positive and resilient mindset. Other findings also imply that sexual development in youth with disabilities is a major concern for them and should be sensitively and adequately addressed if resilience inoculation is to be successful. Finally, it was found that long term caring for the disabled is a heavy responsibility and could be a source of stress that may have negative consequences on the quality of care for the disabled. All these concerns found in this study could potentially form part of a general framework for those who aim to assist in fostering and developing resilience among youth with disabilities.

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CHAPTER 1

INTRODUCTION

1.1 Background of the Study

The categorization of children and youth with special needs encompasses a wide spectrum of disabilities including giftedness (Santrock, 2008). Congruent with United Nations' definition of youth as those persons between the ages of 15 and 24 years (Youth and the United Nations, 2010), this study focuses on issues of resilience among a selected population of youth with disabilities. These young people face chronic permanent risk to their development which is often compounded by other life adversities (Wiener, 2003). Because they often face multiple risks, youth with disabilities are particularly vulnerable to stress and thus undergo constant challenges to the integrity of their development (Spekman, Goldberg & Herman, 1993).

Elements that can cause impairment to one's development may be present before or after birth. The five areas of concern are physical, language, cognitive, social, and emotional development (Berk, 2005). Genetic abnormalities, infections, or environmental contaminants are among the main debilitating factors to healthy development (Umansky & Hooper, 1998). Due to the nature of interdependence of the five areas, a child's overall development will be in danger or compromised if any one area faces difficulties (Berk, 2005). Individuals who are disabled due to one or more compromised area of development are at-risk of having negative life trajectories and developmental outcomes (Goldstein & Brooks, 2006).

In addition, individuals who are disabled often encounter experiences that lead to stigmatization (Martz, 2004; Young & Mintz, 2008). The feeling of being stigmatized is a psychological process (Harvey, 2001). Goffman (1968) had emphasized stigma was a construction of society more than an attribute of individuals. Riddick (2000) had emphasized that although it had its beginnings in labeling theory, stigmatization can and does occur prior to as well as in the absence of labeling. She further posits that "labels on their own do not necessarily lead to stigma, but that labels can encapsulate or distil the stigmatization that already exists" (Riddick, 2000, p. 655).

Various studies relating to stigmatization among disabled individuals have shown that this phenomenon affects the self-concept. Furthermore, the devaluing extent of disability often cause individuals with disabilities to view themselves "in a position of lower status and unworthy of acceptance" (Ladieu-Leviton et al.; as cited in Martz, 2004, p. 140). Stigmatized disabled individuals also tend to experience the

devaluation of character that can lead to the feelings of isolation, estrangement and ostracisation from the community, purposelessness, and especially if not working, a lack of self-worth (Davey & Keya, 2009; Martz, 2004).

Facing multiple and chronic adversities, youth with disabilities seem to face a bleak future. Historically, resilience research dates back a short 50 years and had only expended significantly over the past 20 years (Goldstein & Brooks, 2006). Fostering resilient qualities in these at-risk children is now seen as one of the ways to positively manage chronic and permanent disabilities (Spekman, Herman, & Vogel, 1993). Resilience is now seen as crucial in efforts to assist in normalizing them as best as possible.

This sense of urgency in resilience research was instigated by two main phenomena. First, the increase in technological complexity caused an increase in the number of youth facing adversity and simultaneously, an increase in the number of adversities they encounter. Second, there has been an accelerated interest among parents and clinical and educational professionals to understand the processes of risk and protective factors, and use this knowledge to establish a “resilient mindset” prior to reaching young adulthood (Brooks & Goldstein, 2001). The main area of investigation for this study focuses on how stigma influences the resilience protective factors for individuals with disabilities.

1.2 Statement of the Problem

Normalisation entails the effort to deinstitutionalise and effectively place suitable individuals with disabilities in integrated schools, communities, and work places. This endeavour requires a certain degree of independence and general social and emotional well-being of the disabled individuals (Winzer, 1996). In Malaysia, medical diagnostic and mental health clinics, community-based rehabilitation centres and special education programs in schools have all been activated and operational within the community, assisting in the care and normalisation of individuals with disabilities (Bahagian Pendidikan Khas, 2009).

Literature had clearly shown that major difficulties to this normalization process include social stigma relating to the disability, low self-esteem, depression, lack of socializing skills, compromised problem solving skills, and uncertain resource support (Goldstein & Brooks, 2006; Winzer, 1996). Although empirical evidence is lacking with regards to delinquency among disabled children and youth in Malaysia, local news reports had highlighted several cases of sexual assault on deaf children and youth (Berita Harian, 2003; Malay Mail, 2007). There were also signs that sexual criminal misconduct being committed by individuals with disabilities (The Star, 2007; Utusan Malaysia, 2003).

In addition, there are also problematic issues of maladaptive behaviour and social isolation among children and youth with disabilities who attend local public schools in Malaysia. Teachers at special education programs noticed that many parents are extremely reluctant to take their disabled children out on recreational

outings or social gatherings. This causes a kind of stigma and social isolation among these students with disabilities which can subsequently undermine efforts to socialize and normalize them (Umansky & Hooper, 1998; Winzer, 1996).

Additional social issues include bullying, smoking and sexual experimentation among the general youth population in Malaysia are becoming increasingly common (Abdul Majid Ismail & Roziah Abdullah, 2003). In recent years, intense societal challenges such as economic instability, local and global social unrest, and difficult political climate are also traumatic and stressful life events that have caused social, medical and educational professionals to be concern for children and youth of today. It has also resulted in an increase in their intention towards instilling resilient behaviours (Greene, 2007).

Clearly, the local contexts in which children and youth with disability grow and develop today are becoming increasingly challenging. Our young people with disabilities need careful and timely guidance in their daily efforts to overcome the risks they face as these challenges have the potential to negatively influence their final developmental trajectories. Research has clearly demonstrated that developing resilience among individuals who are at-risk, substantially increases their chance of a more positive life outcome (Hammond, 2008; Hjemdal, Friborg, Stiles, Martinussen, & Rosenvinge, 2006; Masten, & Reed, 2002; Murray, 2003).

As such, this study aspires to understand contextual problems occurring among children and youth with disabilities in the effort to develop a resilient mindset that is

able to weather life's adversities. The aims of this endeavour are encapsulated within the objectives of this study.

1.3 Purpose and Objectives of the Study

The purpose of this study is to investigate the influence of stigmatizing experiences on the protective factors of youth with disabilities. It has been constantly shown through research that protective factors are important to the development of resilience. Additionally, stigmatizing experiences has been chosen as the instigating stress factor or adverse life event due to its pertinent presence among individuals with disabilities. In order to achieve the purpose of this study, below is the list of four research objectives:

- a. Recognize any distinct phenomena in the resiliency profile of youth with disabilities.
- b. Identify characteristics of stigmatizing experiences of youth with disabilities.
- c. Investigate the influence of stigma on the internal protective factors.
- d. Investigate the influence of stigma on subsequent interaction with external protective factors.

1.4 Research Questions

Based on the objectives already stated, the research questions below are formulated to shape the research to provide empirical evidence in addressing the issues highlighted in the 'Statement of Problem' section.

- 1.4.1 What distinct phenomena can be identified in the resiliency profile of the respondents?
- 1.4.2 What are the characteristics of their stigmatizing experiences?
- 1.4.3 In what way does stigmatizing experiences negatively influence respondents' internal protective factors?
- 1.4.4 In what way does stigmatizing experiences influence respondents' interaction with their external protective factors?

1.5 Research Framework

A research framework would ideally consist of both a theoretical and a conceptual framework. The theoretical framework of the study serves as a basis for conducting research and is a structure that can hold or support the theory of a research work. It presents the theory which explains why the problem under study exists. The theoretical framework is also essential when preparing a research proposal using either descriptive or experimental methods. Among its other purposes are to assist the researcher to see clearly the variables of the study, and later to provide him with a general framework for data analysis.

The conceptual framework is formulated based on the theoretical framework. Whilst the theoretical framework is the theory on which the research is based, the conceptual framework is the operationalisation of the theories within that theoretical framework. A concept is said to be an image or symbolic representation of an abstract idea. Chinn and Kramer (1999) described a concept as a complex mental construct that depicts one's experience. Thus a conceptual framework is the researcher's own position on the problem and explicitly gives direction to the study.

A conceptual framework may also be an adaptation of a model used in a previous study, with modifications to match the inquiry. Aside from showing the direction of the study, through the conceptual framework, the researcher is able to show the relationships of the different constructs that he wishes to study.

1.5.1 Theoretical Framework

The basis for conducting this study is expressed within its theoretical framework which includes the elements of the human ecological systems, stigma, and resilience. The basic theory that guides this research is Bronfenbrenner's Ecological Systems Theory of human development (Berk, 2005; Bronfenbrenner, 1979; Santrock, 2008), primarily concerning the micro and meso systems of the target respondents.

In addition, the theoretical framework for conceptualizing stigma comes from the Three-Dimension Stigmatization Framework (Heatherton, Kleck, Hebl, & Hull,

2003). This framework contains three main dimensions that include inter-relational, psychological and social identity (Heatherton et al., 2003).

The third element that forms the theoretical framework of this study is the resilience model conceptualized by Richardson and others (1990), who consolidated years of accumulated research on resilience and resiliency. Similarly, a Youth Resiliency Questionnaire (Donnon, & Hammond, 2007) based on a well researched list of internal and external protective factors that literature had shown to be important for the long term development of resilience will be used (Earvolino-Ramirez, 2007; Goldstein & Brooks, 2006). These theories will also form the general framework for data analysis and in deciding the methods in the methodology section of this study.

1.5.2 Conceptual Framework

The direction of research for this thesis is conceptualised within the theories stated above. The area of human ecology that concerns this study sits mainly in the domain of the microsystem which includes the self and direct interactions with family, peers, school, and others. As seen in Figure 1.1 (Santrok, 2008 p. 49), the individual being situated within the microsystem would, according to Bronfenbrenner's theory, also be subjected to bidirectional influences from all other three ecological systems (Bronfenbrenner, 1979; Berk, 2005). This depicts that the flow of influence can come from either direction.

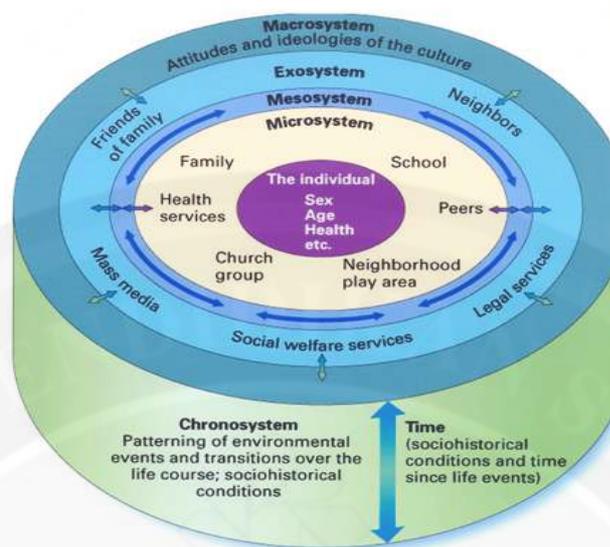


Figure 1.1 Bronfenbrenner's Ecological Systems.

What is being studied here is the influence of stigma on respondents' internal and external protective factors, which have been indicated by research to be crucial for the healthy development of resilience (Donnon, & Hammond, 2007; Earvolino-Ramirez, 2007; Goldstein & Brooks, 2006). The conceptual framework in Figure 1.2 has been operationalised to show the path of stigma's influence on resiliency. This study conceptualizes that stigmatizing experiences usually impact the individual's internal protective factors first, then subsequently, impacts upon the individual's external protective factors.

This conceptualization has its foundation from the evidence that stigmatization is a psychological process (Harvey, 2001; Young & Mintz, 2008), which most significantly impacts on the self-concept (Martz, 2004), one of the internal protective factors. However, how this phenomenon subsequently affects the individual's interaction with his/her other internal and external protective factors