Perceived stigma in young people with intellectual disability

Introduction

Previous studies have shown that the psychological disorders in people without Intellectual Disability (ID) can also be identified in people with ID. Young people with ID have been observed to have more serious psychopathological problems compared to those without ID (Einfeld & Tonge, 1996; Einfeld, S. L., Piccinin, A. M., Mackinnon, A., Hofer, S. M., Taffe, J., GrayK.M., et al., 2006). A survey study found that mental problems in people with ID showed a higher prevalence of affective disorders and anxiety disorders in young people with ID than those in people without ID (Emerson, 2003).

Matson and Barrett (1993) presented several categories in the psychopathology of people with mental retardation, including anxiety disorders, affective disorders, conduct disorders, self-injurious behavior, hyperactivity, schizophrenia and so on. Psychopathology in people with ID is a complicated issue intertwined with different causes and types, and very difficult to treat among such a population group. In addition, arising problems always leads to an increase of enduring stress in their parents or caregivers (Hasting, 2002). Therefore, treatment and improvement of the psychological disorders symptoms will not only promote social adaptation of people with ID but also release the stress of the caregivers.

Researchers have found higher rates of psychopathology for individuals with stigmas compared with the general population (Pachankis, 2007). Dagnan and Waring (2004) found that psychological distress in people with ID was associated with their perceived stigma. Szivos-Bach (1993) also demonstrated that increased awareness of stigmatization was related with low self-esteem which is constantly a part of depression.
in adolescents with ID. In the psychological perspective, social stigma may cause psychopathological problems in people with ID.

People with ID may always sense stigmatized treatment throughout their lifetime. Young people with ID may feel rejected or have discriminated treatment by their peers (Zic & Lgic, 2001; Cutts & Sigafoos, 2001; Cooney, Jahoda & Knott, 2006). Due to the negative social construct or confined social environment, people with ID often experience more negative life experiences and have less opportunities in rewarding works or to develop social networks than those without ID (Chappell, Goodley & Lawthom, 2001). Young people with ID constantly need to face discrimination from social stigma, which not only affects their life opportunities but also impacts their well-being. It may become a vicious circle for people with ID to face marginalization and mental problems at the same time.

When it comes to issues regarding social inclusion and the mental health of individuals with ID, their feelings about their perceived stigma should not be ignored. Therefore, great importance is needed to understand the feeling of stigma in young people with ID. This study is a qualitative and exploratory study aimed to gain an understanding on how feelings of stigma are formed and perceived among young people with ID in school and to explore the influence of social stigma on their life.

**Method**

**Participants**

Fourteen young people with mild to moderate ID participated in this study. They were either students or graduates of special education class in a vocational school located in Taitung, a city in eastern Taiwan. Most students in this high school were normal and not designated as handicapped. The students with ID were segregated from peers without ID
and set in three special education classes. Young people designated as being handicapped who were allowed to attend this school must have no more than mild limitations in performing activities of daily capacity in functional living. There was a high chance for the students with ID in this school to enter society and live independently in the future, therefore, it was a great benefit to understand and study their stigmatic feelings.

Three criteria were applied to the selection of participants. First, they had to have no communication difficulties; second, their diagnosis was not comorbid with an autistic spectrum disorder; third, they had no serious physical or sensory impairments and finally, they agreed to participate in the interviews. The demographic data of all participants is shown in table 1.

**Procedure and interviews**

This study was conducted between November of 2006 and March of 2007, fourteen young people with ID who were between the ages of 17 to 22 years old participated in individual open-ended interviews. Informed consent was obtained from the participants and their parents. Semi-structured interviews were conducted. Prior to formal interviews, the investigator visited potential participants on two or three occasions to allow students to feel comfortable with the investigators. These visits permitted the investigator to spend time with participants at their school or workplace. Sometimes the investigator accompanied students on errands to leisure activities. In addition to gaining a trustful relationship, in order to facilitate the flow of dialogue in interviews, the researcher also tried to obtain information about the participants from their teachers to understand the background and context of the participants’ lives.

Each individual was given one to two formal interviews, each lasting a minimal of 50 minutes. Because the purpose was to study how social stigma influence their life, the
interviews covered three areas: (I) the participants’ experience of stigma in school, (II) how they viewed stigmatic treatment in school and (III) their responses to the disability-related stigma. Sampling stopped after theoretical saturation was achieved.

Analysis

Apart from transcribing approximately fifteen hours of the interviews, field notes were also recorded. Thematic statements that described stigmatic experience were isolated from transcriptions of the interviews and field notes. Using the complete set of phrases, sentence clusters and field notes, data were then analyzed through grounded theory and finally reduced into essential themes. The process of data analysis was checked by two experts in qualitative research and the findings were confirmed by the school teachers of the young ID individuals.

Result

The three themes included, feeling different and confused, stigmatized identity and behavioral implication were conceived in regards to the formation of stigmatic feelings among young people with ID in high school.

Their perceived stigma was accumulated and constructed from negative interpersonal interactions during childhood, results of school work and responses from teachers. These experiences caused them to feel different from others and a sense of confusion. Making matters worse, obtaining the handicapped card for most participants only promoted and embedded their ID identity and abnormality. In their perspective, people around them were divided into two segments, either the normal and abnormal group or sick and non-sick group. It was found that the participants viewed themselves from the evaluation of others and then come to recognize themselves as abnormal and ill people. Invisibly, stigmatized identity was formed through their school experiences. Social stigma not only
affected participants’ living experience but also influenced their cognition. In their behavioral implication, impression management and social avoidance following the formation of stigmatized identity could be found.

**Feeling different and confused**

As early as elementary school, participants began to feel that there was something different about them in comparison to others at school. The sources of such feelings resulted from their performance in school work, interaction with other people and responses from teachers.

**Negative interpersonal interactions**

Negative interpersonal interactions during childhood result from school interaction. Such experience was described by one female participant in the following terms:

*When I was in elementary school, some day, I asked him (her classmate) how to write a word I didn’t know. After saying one sentence, I feared to continue..., He talked to me loudly. He asked; why are you unable to write words? He spoke loudly...and asked why I did not understand what he was saying... it was frightening...” (B-8).*

Upon looking into the eyes of the classmates, young people with ID felt the initiating of negative interaction.

*In school (elementary school), it was unhappy for us that they (classmates) saw us in strange ways. I didn’t like it and felt embarrassed. Their stares made me feel like a monster! (I-20)*

**Their school performance**

For a number of participants, the performance in school, such as examination
grades, constantly caused young people with ID to attribute themselves as being different from their classmates. Although they always tried to hurdle over this wall and redeem the difference between themselves and their classmates, it was in vain. One participant expressed his feeling:

*My school work was bad, I felt... I had always tried to study hard. I thought my classmates are normal, why are we different! I wanted be a normal person, having good ability to think.* (B-9)

From this descriptive content, stigmatized identity appeared from their feelings of being different, making participants feel confused of why they were different.

**Responses from teachers**

Accumulating little by little, responses from teachers often lead to the feelings of being different and possessing a stigmatized-identity in young people with ID. Some participants felt confuse from their teachers’ attitudes. These responses were found when counseling people with ID.

*My teacher always told me, always told me that it did not matter! Like you, this kind of child, you just work hard! Stand up to them (other classmates), then he encouraged me to slowly approach them, approach them slowly! But I always thought what kind of child am I? Why did they tell me in this way? Sometimes, I felt bored. Very bored...* (A-16)

**Stigmatized identity**

After feeling different and confused from the treatments by peers and teachers in school, young people with ID start to believe that they were abnormal or ill. Such identity was further confirmed through the possessing of the handicapped identity cards issued by the government. Most participants came to view themselves from the evaluative behavior of
others. In this study finding, it was found that social representations of young people with ID were stigmatized.

Some participants recalled their thought and emotions after obtaining the handicapped identity card when they were in elementary school:

*Why did I become like this? Why did I have to have the handicapped card? I want to be normal. I wish I didn't need to have the handicapped card.* (A-10)

*The most unhappy thing is that others would see us in a different way. The gaze of others... having a handicapped card made us felt embarrassed. I was not happy, at that time, I felt embarrassed to show that we have a handicapped card.* (J-13)

*I thought I was not happy. I felt embarrassed to tell them (their classmates) I had a handicapped card. I thought I was really an idiot.* (K-9)

Furthermore, after being issued the handicapped card, young people with ID would enter special education classes in elementary school. For most participants, the special education classes were in terms of a resource room. A resource room program means that students with special educational needs still had to spend most of their time in regular classes, whereas only a small fraction of school period was spent on receiving special education services with other classmates that have special needs. It seemed to be an embarrassing experience for most participants to enter resource rooms and allow their regular class classmates to acknowledge their abnormality and differences.

*Everyone said that only an idiot could enter this room (resource room). When my teacher told me that I should go to the resource room at three o'clock every afternoon... I suddenly realized that I was an idiot. I felt like crying at that time.* (G-11)

Sometimes, there was tension in their mind especially for participants who denied they were people with ID. Participant who viewed himself as superior to their peers with ID in
resource rooms wished to dissociate themselves from special classes but sometimes they would prefer to stay in special classes because of the exemption from tuition fees and less demand on their school performance.

There were many advantages to stay here (resource room). Some classmates in the regular class envied me. They often asked me why I could be there. There was not a lot of homework. There were a lot of free things. However, sometimes I felt ashamed when classmates dismissed class. Sometimes, I wanted to escape out of class. Sometimes, I felt that I was not the same as the classmates in this room. (F-13)

The meaning of being different for some participants was that they were ill people. One participant described her family situation and stigmatized identity.

There were five children in my family. My younger brother and sister were studying in elementary school. They were normal, without handicapped cards. Other children, like me, were ill and sent to special classes. (L-6)

Another participant described the experience of using the handicapped identity card. She thought it would not be an embarrassing thing to take out her card in the hospital.

I seldom took out my card even when I am buying my monthly season ticket at the bus station. Nevertheless, I do not fear using it in the hospital. Undoubtedly, it was normal for a sick person to be in a hospital. I felt more comfortable to show my card in the hospital, ....I didn't know why...!(I-12)

Although the handicapped identity card was a social welfare policy, it strongly caused the labeling of people with ID as they received social resource such as entering special education classed. Thus, being issued a handicapped card caused serious mental distress, especially on the young people with mild ID.

Behavioral implication
It was found from interviews that participants’ behavioral reaction to discriminated treatment was distancing themselves from the stigma. Often, they would attempt to keep an impression of themselves in order to conceal their identity. On the other hand, they tended to develop friendships with other ID individuals to buffer the impact of stigma. Such a cycle could gradually become a type of social isolation.

**Impression management**

Participants expressed that they fear and avoided to take out their handicapped cards or present it to others, especially when buying transportation or movie tickets.

*I did not want to let him (the person she liked, a normal person) to know that I have a handicapped card. Therefore, I hid my card in a secret place and did not put it in my wallet. (K-9)*

Some participants used a dodging strategy when encountering stigma. One young people with ID showed that she always asked someone she knew to buy bus tickets for her because she wanted to hide her ID identity. This way, she would be able to keep those from knowing her ID identity at a minimum.

*When buying bus or plane tickets, I must ask help from my parents, friends or brothers to buy the tickets for me. I didn’t buy the ticket by myself not because I could not do it. Really! It was an easy thing for me! I just dislike it. Sometimes, I thought the clerk would be laughing at me in his mind and wanted to know why I had a card. I was ashamed to let a lot of people know I was a disabled person by taking out my card!* (E-16)

One participant also indicated that she would always restrain her classmate from showing idiotic behaviors such as doing clownish dancing on campus. She thought students in normal classes would acknowledge her ID identity due to her classmate’s behavior.

*I tried to call him back into class. I wouldn’t allow him to dance like a clown*
outside of our class. It was embarrassing for us, and students in the normal classes would think we were like him (K-20)

From the interviews, some participants also emphasized their achievement in learning to counteract and cover their stigmatized status. However, the achievement they described was also the thing that they lacked ability to do. As one participant stated:

   I liked to repair things such as a motorcycle or bicycle. If your motorcycle does not work properly, you could tell me and I could fix it, it’s true! I like to repair things. It would be happy to repair things. (however, his teacher told the interviewer that this participant’s ability to repair things was poor) (A-25)

   I wanted to learn the computer. Would you please tell me where I could learn the computer? This way, I can be like the normal people! (C-15)

Social isolation

They felt insignificant due to their difference and drew back from those with normal intelligence. Their self-attribution also affected the formation in their peer relationships. It was easier for them to be friends with people with ID than to make friends without ID.

   Sometimes, I was afraid to make friends with a normal person, I feared they (normal person) would dislike us” “I still liked to be together with people like us, we knew each other better! (B-21)

Sometimes, they were afraid of talking with normal people which may force them to show their ID identity. Many times, such a fear enforced their isolation even more.

Discussion

In line with findings of previous studies (Jahoda et al.1988; Rapley et al. 1998), young people with ID had to face and cope with stigma in their everyday life. A lack of
acceptance or experience of discrimination in school was a major concern to them. When participants were out of school, they might be in the situation of concealing the stigma; however, as they attend school and enter their classes, stigmatized treatment was constantly around them. Because the participants’ classes were designed especially for them, and placed in a special area in their school, it was easy for them to be in a stigma-discovered situation. Thus, it can lead to negative consequences when young ID individuals enter situations that easy allow others to discover their intellectually-disabled secret. Individuals trying to conceal stigma may encounter substantial psychological difficulties (Pachankis, 2007). Furthermore, some participants expressed an emotional reaction of anger, frustration and hurt when talking about their experiences of prejudice in school. Stigmatic experience seemed to cause various psychological problems. Hence, it is vital to teach young people with ID how to heal with stigmatic experiences in school and schools should provide mental health interventions for them.

The findings of this qualitative study was consistent with Crocker & Quinn’s view (2000) that the negative impact of stigma not only is the result of direct social experience but may also affect their cognition such as self-evaluation or self-concept. The meaning of stigma for a person is influenced by social factors and psychological process as well. One comes to view oneself from the evaluative behaviors of others. In this study, social representations of a special group such as young people with ID were stigmatized. Constantly, participants perceived themselves ill or abnormal people and stigmatized identity was further confirmed by possessing handicapped identified cards issued by the government. People holding handicapped identified cards can receive social welfare in Taiwan. Nevertheless, some participants, especially those with mild intellectual disability, still expressed in the interview that they wanted to give up their card if possible. Therefore, whether or not to issue handicapped identity cards to people who are
diagnosed with intellectual disability should be discussed and re-evaluated. It becomes crucial for young people with ID to receive psychological counseling when issuing them the handicapped identity cards in school. In the future, the impact of owning handicapped identity cards to people with ID should be evaluated in Taiwan.

Forty years ago, Edgerton (1967) began to focus his studies on the stigmatic problems in people with ID leaving long-stay hospital. He showed how a stigmatic feeling may affect their cognition and behaviors. However, there are little researches about stigma in people with ID in Taiwan. This may show that the themes about mental health during social adaptation in people with ID are seldom emphasized in Taiwan. Social adaptation for people with ID always begins at the point of school admittance and consequently it is important to monitor their psychological problems caused from personal interactions in school. Feelings of stigma affect social inclusion in young people with ID. It is important to treat the stigma problem when counseling young people with ID in school. Furthermore, the relationship between psychopathology and perceived stigma in people with ID should be given a greater importance in future research.
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Reference


social –cognitive model of the experience of people with intellectual disabilities.

*Clinical Psychology and Psychotherapy*, 11, 247-254.


