

“I’m not a Rice Pot”: Disability, society and inclusion in Hong Kong

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Abstract: *This paper reports Darren’s story told from the perspective of a person who, due to a serious accident as a young adult, became a quadriplegic. Darren experienced debilitating consequences as a result, which led to many challenges for him in both social and work activities. His limited mobility directly affected his job prospects and personal life. By sharing his life experiences and the personal difficulties he faced, Darren’s story highlights the difficulties of young people who are physically disabled in Hong Kong. It is a story of hope and encouragement, although it began with one of frustration, depression, and boredom.*

Key words: *People with disabilities, having a disability in Hong Kong, rice pot*

1 Introduction

Personal stories of people with a physical disability from China and Hong Kong, have presented them as heroes (Dauncey, 2012). A new trend noted in personal stories of people with a disability, however, presents the person “living a productive life, the need to challenge preconceptions about disability, and an enhanced sense of self and self-worth” (Dauncey, 2012, p. 312). Darren’s story is the narrative of such a person living and working in Hong Kong, and is a story of transformation from his dependence after the accident, to regaining autonomy. He is an active decision maker, who considers that he fights against the ideas of Hong Kong Society, namely, that he is merely a recipient of care, as Darren is quadriplegic. This article, therefore, adds to the growing number of personal stories from people with a disability living and working in the different cities in the region, although Darren’s story is one of the first to be publicized from Hong Kong.

In writing his story, he felt that one of the important aims was to bring the contemporary attitudes of Hong Kong society to light, particularly from the perspective of a person with a physical disability. Darren feels that he fights against the ideas of Hong Kong Society on a daily basis. Furthermore, in co-writing with Darren we have learned from each other and developed a deeper understanding, respect and commitment to support others with a disability in Hong Kong. The title of the article “I’m not a rice pot”, therefore, is a positive declaration by Darren about himself and his friends with a disability in Hong Kong, who also strive to support themselves through their own efforts. Darren’s emphasis is that he is a productive member of society who fulfils his own expectations for independence, as well as the filial expectations of a son or daughter in Chinese culture.

2 Chinese perspectives and disability

Within Chinese and Confucian culture, parents provide for their children and it is commonly expected that when parents become incapacitated, the children will provide for their needs (Yang & Kleinman, 2008). This particular cultural perspective, according to Yang and Kleinman (2008), places a high obligation and moral duty upon the children to provide for their parents when they have retired, and even after their death, particularly on specific festival days, such as *The festival of the Hungry Ghost*. Being a son or daughter with a disability, therefore, can be considered a judgment on the whole family, especially if the person’s disability means being unable to carry out expected filial duties, as might be the case for someone with quadriplegia. In addition, there are traditional cultural perceptions of disability, which have viewed the disability as retribution for the person’s early transgressions, past lives, or as a punishment for the past sins of parents or grandparents (Yeung, 2008). Furthermore, in Chinese culture according to Stafford (1995), the term *rice pot*, has been used to indicate a person who does not provide for his or her parents when they grow old. The analogy is that the individual eats the rice provided, but does not pay for it, in this instance, providing for parents when they are no longer able to care for themselves. The term is commonly used in the Asia Pacific region in a derogatory fashion to indicate a person with a disability.

3 Having a disability in Hong Kong

Of the extant studies conducted about people with a disability in Hong Kong, Yeung (2008) found three categories of people who had survived work injuries that left them permanently disabled. Yeung (2008) described the people as survivors, achievers, or strugglers. Each person, however, individually negotiated the constraints and

opportunities of living with a physical disability in what Yeung (2008) portrayed as “against the odds”. According to Yeung (2008).

The sense of shame and the moral connotations that the disability brings to the sufferer and the burdens he or she carries with her or him on social encounters might make the experience more complicated. The intrusiveness of the disability undoubtedly plays a part in how the disabled person and the people around him or her respond to it (p. 851).

People with a disability and wheelchair users’ perceptions of their quality of life in Hong Kong, linked to their participation in the community, for example, their ability to access public transportation and their engagement with family and peers, rather than the users satisfaction with their wheelchair (Chan & Chan, 2007). Furthermore, the ability to cope with a disability found amongst community-dwelling elderly persons in Hong Kong was positively related to their level of education (Choi & Leung, 2008).

4 People with disabilities

Self-determination

Traditionally, it has been the role of parents to bear the responsibility for their children with disabilities into adulthood and to provide them with a home (Berry, 2009). The promotion of this rights-based approach has been embedded within legislation in many regions throughout the world, thus people with disabilities in general have become more self-determined in seeking opportunities for living independently within their community with support. In Hong Kong, current rehabilitation services are still embedded in the traditionalist perspective of paternalism, which perceives people with disabilities as being dependent and helpless, and far from the ideals of inclusion, dignity and independent living promoted in Western societies (Lee & Lee, 2006).

Adaptation and response

The stage theory of adaptation and response to disability (Livneh & Antonak, 1997) purports a gradual assimilation of an altered identity that is an on-going process that is developed over a life span. Further, Berry (2009) suggested that there were many challenges to the relationships people with a disability have within and outside their family, particularly in seeking meaningful employment. Adjusting to a sudden traumatic acute onset of disability, as a result of an accident, requires an immediate reorientation of personal priorities and relationships. A lack of anticipatory adjustment aligned with the sudden onset of a disabling condition, compounds the way in which some individuals respond to a sudden and dramatic change in their life (Smart, 2009). In many instances, though, people with disabilities report that it is

not the disability per se that causes them the greatest stress but the prejudice and discrimination of society that they now encounter (Smart, 2009).

Expectations and opportunities

A society that is less than supportive of people who are disabled often precludes those with a disability from equality of access and participation. Darren's story, though, explores how being disabled does not necessarily prevent the undertaking of expected family duties, as long as that person is given appropriate opportunities to do so. Darren exceeds cultural expectations of people with disabilities in Hong Kong, who are often considered unable to provide a means for self-care or to support their parents in old age (Yang & Kleinman, 2008).

As a mechanical engineer and assistant general manager of a large firm in China, Darren worked very hard, he entertained and socialized with work clients on a regular basis. He lived in the community and spent a large amount of travelling around. His story explores how his life changed after being involved in a serious car accident.

5 Method

We contacted numerous community groups to find a person with a disability who was willing to share their story. We specifically sought a person who had paid employment. Going through community groups produced no results, and it was by word of mouth that we heard of Darren. From our initial contact, Darren was keen to participate in writing his story so that he could share with others how challenging it is for him to live and work in Hong Kong.

We sought details about Darren's experiences, and the challenges he had faced, the support he had received and how he had overcome any barriers to being included in the work force. The material used in the article was gathered through two interviews that lasted for up to 45 minutes. Darren's story was written based on these conversations.

All interviews and subsequent meetings were recorded with Darren's consent. We discussed the aim of the interviews with Darren before recording. During the interviews, we gave Darren encouraging non-verbal signals, and for the most part, remained silent during the recording. The interviews were transcribed and sent to Darren by email. We met with him on several occasions in order to clarify certain parts of his story, and the meaning he wished to convey. These meetings took place at Darren's workplace and were conducted in a mixture of Cantonese and English. When it came to writing his story, we sought further explication on any translation issues and meaning. Thus, Darren was closely involved in reviewing and amending the text in an iterative process that involved emails, telephone calls and face to face

contact. To maintain the authenticity of the story, we have, with Darren's agreement, used his own words recorded in the interviews.

6 Darren's Story

I was born in China. I have an elder brother, a younger sister and a younger brother. It was a very poor village so I wanted to have some high career or post for my future. I thought being a pilot was good – quite professional and prestige.

I moved to Hong Kong with my mother and brothers when I was nine years old. On leaving school, I studied mechanical engineering to become a pilot. I have a higher certificate in engineering. I then joined a company of plane maintenance. Because my English and my study results were not very good, it was quite difficult to get a pilot license. So I quit. I then joined another company doing project engineering for seven years, handling toy car designs, putting them to manufacturing lines, and making shipment arrangements.

In the meantime, there was a migration wave and I was one of the Hong Kong people to move out to go to Singapore. I joined a semiconductor manufacturer as a mechanical engineer doing automation. I designed the machines that ran the whole production line. That was in 1997 to 1999. Then, I came back to Hong Kong and joined another company doing craft paper manufacturing in China.

The traffic accident happened in 2000. As the factory was in China, I needed to travel around the mainland. My post was quite high (assistant general manager). I needed to meet everyone and needed to entertain others. I remember at that time I got quite a number of glasses of red wine. I slept in the car. My driver drove me back. On the way, he avoided a car coming towards him from the opposite lane. My car was bumped to the side of the road. I could not move my legs and I had a spinal cord injury from C5 down.

My parents took care of me to 2007. They coped with my disability by first looking to see if there was some kind of cure available. Maybe there was a treatment that will make me as before. Maybe I will walk again. Maybe to have fingers that can move. Maybe no need to use the wheelchair. So many movements I cannot do. My brothers and sisters often just say to me "What you want you just tell me. I will do them, if I can." I know as long as they can do it, they will support me.

Before my accident, I got a girlfriend. We almost got married. After the accident, she said she could not be with me. So, she left.

My life was even worse than before. I just only stayed home, and my family's friends came to visit sometimes. I woke up at twelve, and then slept maybe at two, got nothing to do, and just faced the computer.

I wanted to find a job because it was very boring at home. I could play the MSN or send some instant messages, but it was not enough. I am a human being. I need to have some community integration. I need to meet people outside my home. I had many friends but I lost many friends. Before my accident, I had many friends drinking outside Lang Kwai Fong or Tsim Sha Tsui [bar areas in Hong Kong]. But now, they have grown and they have families, and they need to be responsible for their families. So, we become quite distant – not as close as before. We get together once a year.

For the first four years I did not have any job. So, I stayed home. I tried to study. Internet was a big thing for me at that time. I was able to find information about different medical equipments. I did not need to go out to get the information. At the same time, I wanted to be mobile. I am in a wheelchair. Therefore, my first concern is accessibility. “Where is the way I can go?” Thinking of bus routes or MTR [Mass Transit Railway in Hong Kong], I often need to ask myself, “Is this a suitable way for me to travel?” “Which exit is good to me?” For the manual wheelchair users, it is quite hard. Now, once I am on the computer, I can find Wan Chai or Tai Po [two areas in Hong Kong accessible by MTR], let you know where the exits are, and the best way for wheelchair users to travel in those areas.

Money became a concern when I started to get out of the house and meet people. Getting a cup of coffee was about ten dollars at that time. Now, a regular Starbucks coffee costs about thirty dollars. Therefore, I told myself, Oh! I should get a job and get some money.

Because of my mobility, I believed I did not have many opportunities in getting a job. So, I started by applying for jobs in the government. I thought the government would support me, but I was wrong. After spending almost a year, I believe the government never supports employment of people with disabilities. If the government thinks you are independent, then you can do the job. If you are dependent, then the government will think that you are incapable in doing the job. I tried mailing 40+ letters applying for jobs in the government, jobs like answering hotline, but I was not even able to meet their requirements.

I realized that the government was not going to give me a job. So I stayed home, got on the computer and MSN [MicroSoft Network – Windows Live Messenger] my friends. Then, one of my friends told me about a company looking for sales representatives. So I prepared myself for an interview. I think that was March, 2005. The company offered me an interview, and then confirmed my employment the next day. I later found out that a very generous person, who owned another factory, started this company. He used some of his profit from his first company and started another company with a focus on hiring people with disabilities. My job was about order receiving and making shipments and delivery arrangements. It was a full salary position. The salary was six thousand dollars [Hong Kong] a month. That salary was not subsidized by the government.

There were another eight people with disabilities working in this firm. I think that was a big firm. In Hong Kong, the company had 60 employees, and in China, more than 2,000 employees. I was in that position for four years. The best thing about the job was that I met the best boss. He was a very nice and kind boss. He was the best boss because he was the only one who would employ me. He specifically asked to hire me. I know he has interviewed a lot of people, but he specifically said he wanted to hire me.

There were two groups of people in the firm; people with disabilities and people without disabilities. We worked together in the same place and we met daily. Some of the people without disabilities did not cooperate with us, but some of them were cool and nice. Some of them did not discriminate people with disabilities in the surface, but I know inside their mind or behind our back, they did not like us.

That job was too simple for me; just work on the screen, maybe in small groups. I tried to have a tough job. On 2 Jan, 2009, I became the first employee of a new enterprise and started this challenging job where I am now. I think I need a challenging life. In the present job, I can do everything and use my own ideas. I missed my old job, but I wanted another new start. I missed my co-workers very much, especially the boss.

Since 2004, the year when I started to go out, I have really realized the disability life – living with a disability – is a hard life. I have tried to breakthrough this. Now, I meet a lot of people.

Having a job, I moved out from the family and started to live independently. I live in my own flat. It is from public housing. The government has changed the flat physically for me so that I can access it. They removed the curve from the main entrance and modified the toilet so that it is now big enough for a typical wheelchair. They also widened the door of the kitchen so that I can go in and turn on the water tap or get something from the refrigerator. The electric switches have also been lowered such that I can reach them easily. I do not have any helper to come to my home. Sounds very independent, but actually, I am not. I live with my girlfriend. I cannot do all the cooking and the cleaning. I can cook and I cooked well before the accident. I think if I have some modified tools, I can cook again. My cooking is delicious.

I met my present girlfriend during my reassessment trip in 2003. I think it was love at the first sentence. Although she sometimes scolds at me saying, “Why do you always leave a mess for me?” or “Why is it always you every time?” I know what she is trying to say is, “You must keep in good condition by yourself. Don’t just ask for help from others. You must prepare yourself well for the future. You have to take responsibility for yourself and take care of yourself. Don’t depend on others.” I learn and live by these principles in my community.

As a human being myself, I ask myself, “Why not I earn money by myself? Why not I contribute something to the community, earn some money and have a good

life?" I have the ability to get a job, work hard and get financial security. I can do it by myself. It's OK.

Nowadays, I can see there are mainly two kinds of attitudes towards people with disabilities. The first kind is they will bypass us as usual, treating us as a "normal person". The second kind is they will stigmatize or reject us. They will scan us from head to toe. Many of these people think that we are trouble-makers. They will also say something to make you feel bad. My response towards them is "you can do what you want to do but I don't care". My perspective is that many people still do not understand the true meaning of "integration of able-bodied and disabled persons". For instance, the wheelchair-parking slot in MTR should not be labeled for wheelchair user only. In fact, anybody who needs that space can also use it e.g. baby car. All the transportation, buildings and facilities should be designed fit for everybody instead.

I like meeting people, and through this association, I have got many opportunities to meet different people by giving Life Education talks and giving out souvenirs in different schools and universities. There are 600 members in this association; all in wheelchairs, highly dependent and all have their own life stories to tell. We team up, tell our stories and show the students how to overcome difficulties in their studies or in their lives. For the past 10 years we have talked at more than 600 schools and have met more than 100,000 students.

7 Conclusion

Darren's story shows his strong personality and self-determination in moving his life forward in a positive and engaging manner. Even so, he encountered many challenges, particularly in being given the opportunity to demonstrate his abilities because of his physical disability. It is difficult to see how a person who might be less self-directed could achieve similar outcomes to Darren, as there seems little in place to help support people with disabilities to achieve a fulfilling life within the Hong Kong community. Darren would seem to have what Stienstra and Ashcroft (2010) refer to as a strong 'spirit', that helps to guide and support his achievements, regardless of his disability. Stienstra and Ashcroft (2010) propose that disability is only one aspect of a person's experience that shapes what it means for them to be human, and that a clearer understanding is obtained only when a person's spirit and experiences of spirituality are incorporated into the dialogue. It is Darren's optimistic approach to life, his strong spirit, and academic ability that has enabled him to find a work niche that gives him the prospects he sought to fulfill and fired his desire to join the work force in a productive way. Nonetheless, he still faces many daily challenges and is especially disturbed by the less than positive attitudes he experiences by people whom he meets in the community. His determination to be independent and his

persistence against the barriers that he endures to achieve this, are tantamount to how challenging life as a person with a disability can be. It is difficult enough being disabled, but to have to fight so hard to achieve what non-disabled people expect as their right, highlights the distance that society in Hong Kong still has to travel in order to become a fully inclusive society.

In Hong Kong there are several ordinances that cover discrimination related to sex, marital status, pregnancy, race, family status and disability. The Disability Discrimination Ordinance (DDO, 1995) outlines a wide range of potentially discriminating actions against people with disabilities that are deemed to be unlawful under the Ordinance. Increasingly, people are becoming more aware of these ordinances yet, while it is possible to make people conform to the physical requirements, it is very difficult to address society attitudes, which as Darren highlights remain negative and unsupportive. If Hong Kong is to become an inclusive society, then disability needs to be seen as a human rights issue where barriers for people with disabilities

Can only be removed by the concerted and integrated effort of the government, NGOs, corporates, movie mughals and educational institutions. It is the duty of the rest of society to acknowledge the rights of the poor and the disabled. This can no longer be treated as philanthropy but is a responsibility (Isaac, Raja, & Ravanan, 2010, p. 627).

According to Grech (2009), interventions and support for people with disabilities, though, requires a closer investigation of each individual as “Engaging with what surrounds disabled people (sic) and their families is pivotal, since, like other groups, their experiences and the possibilities and limitations they confront are largely contingent on the broader socio-cultural, economic and political environment” (p. 775). The role of social networks and community services would seem to be key to the reintegration of people following a disabling event and in particular are found to be closely associated with enhanced quality of life opportunities (Chan & Chan, 2007); yet these at present, and according to Darren’s experience, seem to be less developed and even missing from the Hong Kong community.

While Ordinances such as the DDO in Hong Kong can provide legal directions, this must be supplemented by a well established and resourced network of peripatetic staff to ensure the rights of people with disabilities are enacted. Thus, to prevent long-term demands for care services, activities of daily living might be better supported from an early age to enable people with disabilities in Hong Kong to live within their local community (Choi & Lung, 2008).

In some countries such as the UK, rehabilitation services have begun to focus more on user-led funding models that allow people with disabilities to retain dignity and achieve greater equity by being able to remain independent within their com-

munity. Prideaux, Roulstone and Harris (2009) argue that if people with disabilities are able to access locally monitored funding and services and that if they are seen as employers of services rather than benefit claimants, the outcome will be a change in perception of disability and much greater opportunity for them to live more self-determined and thus more equitable lives in society. Choice and control over a person's own life is even more important for those with disabilities, as too frequently this choice is taken away from them. For people with disabilities, being able to choose their own support and life direction has been found to improve health, independence, and positive relationships with family and peers (Rabiee & Glenninning, 2010).

Stories written by people with disabilities, like Darren, who have experienced the challenges posed by a less than sympathetic society, are important for ensuring that relevant stakeholders take on the responsibility for identifying individual needs and in removing barriers that prohibit the full inclusion of people with disabilities within their local community and society. Darren's story also highlights the key importance of self-determination and choice, receiving access to appropriate support, and the availability of strong social networks. His story clearly demonstrates that being disabled does not mean being a 'rice pot' and needing to rely on others for his needs.

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8 References

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