

## Researching Disability

### Emma Stone

In this final section of the book, discussion moves away from action and towards research - although everything that is said in the following contributions has direct relevance to the implementation of disability and development programmes.

All too often, disability and development professionals are funded to "go in and do", without first identifying:

- a) what already happens in the locality (outsiders often assume that there is a blank sheet on which to write at will);
- b) what local needs are - not just for disabled people, and not just in relation to individual impairments and rehabilitation (e.g. income generating opportunities for all might be the best way to support disabled people and the wider community);
- c) local concepts and meanings of "impairment"; and
- d) ways in which "disability" is constructed through local culture, values and structures (where disability means social exclusion, diminished personhood, lack of access to opportunities like education, earning, or having a family, etc).

It is important for outsiders to consider the past as well as the present; to prioritise learning from local disabled people; and to recognise that there are many ways of learning about local views and responses - through oral testimony, media, historical records, sacred texts, language, proverbs, policy, actions, and so on. It is also important to think about ways of doing research (see Stubbs), analysing data (see Stone), and using the results to inform action.

## OVERVIEW OF CONTRIBUTIONS

### *Making Connections: Using Stories from China's Villages and Newspapers*

Emma Stone uses stories to highlight the value of making connections between stories or voices and wider contexts (cultural, structural, policy). Use of different

sources and "extraordinary" as well as "everyday" stories is encouraged. The complexities of disability in the majority world are lost if such connections are not made.

### *Disability Policy & Provision in Jordan: A Critical Perspective*

Majid Turmusani explores disability policy, provision and legislation in Jordan, and considers the current situation of disabled people, dominant social attitudes, and the involvement of western organisations in disability-related provision. He offers a useful account of disability services, constraints faced, and the limitations of existing policies and provisions to address the needs of disabled people in Jordan.

### *Ghosts and Germs: Cerebral Palsy in Nepal - A Preliminary Exploration of Cosmology and Disability*

Rebecca Saul and David Phillips explore cultural perceptions of disability in Nepal. They draw on local language and beliefs, and on family explanations and responses to impairment. Connections are made between responses and a "rural-cosmopolitan continuum". Saul and Phillips point to the subtleties of labelling and the complexities that exist in a context of pluralistic belief and healthcare systems.

### *Can Formal Disability Services be Developed with South Asian Historical and Conceptual Foundations?*

M. Miles uses sacred texts and historical records in search of clues on responses to disabled people in South Asian history. He also considers conceptual differences that are often missed when western professionals work in the majority world (e.g. "child" and "play" are concepts rooted in culture), and he criticises the imposition of western schemes on majority world settings.

### *Engaging with Difference: Soul-searching for a Methodology in Disability and Development Research*

Sue Stubbs draws on her experiences as a practitioner doing research with a local team. Among other issues, Stubbs explores the dangers of linking research rigour to written evidence, when oral culture and testimony is the dominant means of communication in many communities. This paper provides a fitting end to the book - a powerful reminder that the best learning comes from

listening to people who live in the majority world, rather than from reading western or western-influenced literature.

## **DISCUSSION POINTS**

- What sources of data can be used to get a better understanding of disability in the majority world? Are there any problems linked to the data sources you could use?
- What research questions would you ask if you were doing research on disability in the majority world?
- What are the characteristics of good disability research (process, outcomes) on the majority world? And how can they be achieved?
- Do you think that "disability", as defined in western disability studies (i.e. social discrimination, not impairment and not located in the individual) applies outside the minority western world?
- Are there any dangers in applying a social model approach to disability in the majority world? Are there any dangers in failing to apply a social model approach to a majority world setting?
- How, if at all, can learning about cultural, social, structural and historical aspects of disability make any difference to disabled people's lives and services?
- What evidence is there in these contributions of a globalisation of disability, and/or a globalisation of disability-related services?
- What practical steps can be taken to limit the dangers of increased exposure to western ideas, slogans and services?

## **Making Connections: Using stories from China as an example**

**Emma Stone**

(Chapter 11 in Stone, E. (ed.) 1999: Disability and Development: Learning from action and research on disability in the majority world, Leeds: The Disability Press pp. 171-192).

### **INTRODUCTION**

Where do we look for understanding or "data" on disability in majority world settings? How do we respond to and analyse the voices we hear, the things we see, the stories we read? Do we look hard enough for links between individual stories and the broader social, structural and cultural contexts in which those stories are situated? Do we actively seek out stories that challenge our own outsider assumptions?

In a recent paper on developing research agendas for disability research in the minority world, Len Barton (1999, p. 37) reminds us that "making connections" between voices and contexts, between stories, situations and structures, is a core component of the research task. My main aim in this paper is to illustrate how such connections be made when studying, researching or working on disability in the majority world. I have written it with students of Disability Studies and Development Studies and future researchers. Along the way, I hope to offer a few insights into disability and development in China.

The stories used are only the tiniest fraction of data generated over nine months of fieldwork in China, in 1995 and 1996. I have written elsewhere of my experiences of doing disability research, methods I used and difficulties I faced (Stone 1997, Stone & Priestley 1995).

### **STORIES FROM CHINA'S VILLAGES**

The first three stories are from China's villages, from parents who have a disabled child. These stories are far from unique. I heard variations on the same theme time and again.

#### **Xiao Lin's Family**

Xiao Lin is a 10 year old boy who lives in Taozhou township with his mother,

father and elder sister; he has a visual impairment. The discovery was made when Xiao Lin was at nursery school and it was confirmed by examination at Shanlin County Hospital. The doctors said there was no cure, but the parents heard of other doctors and went to Wuhu and to Shanghai for further opinions. The family travels to Shanghai every year to see if anything more can be done. To date, they estimate that they have spent 10,000 yuan on medical and associated costs and that is significantly less than they would have spent had the Lin family not got relatives in Shanghai who could do all the telephoning and put them up.

Xiao Lin's parents have heard that it is possible to have an eye transplant but that such treatment is very expensive - probably 100,000 yuan. But it is not something they have completely rejected as a possibility: "we will put all we have into helping him".

Xiao Lin attends an ordinary primary school in Taozhou. His results are good but his mother is anxious that the next school might reject him because of his impairment.

The family has a respectable apartment, good social connections with the local government (Xiao Lin's grandfather was a senior member of the County Government) and a good standard of living compared to others in the town. Still the search for medical help has necessitated more economic activity on the part of the household. Xiao Lin's mother has had to set up a business making and selling breakfast dumplings before going to her regular day job. All of her wages and her husband's (a departmental head in a charcoal company) have been saved to pay for their son's medical treatment.

(Research Notes from a semi-structured interview with the Lin household, Shanlin County Research Project, Anhui Province, Data Code TZ-CD-6, Nov 1996.)

### **Xiao Zhen's Family**

Xiao Zhen is a 6 year old girl with a hearing impairment. She lives with her mother, father and younger sister in a small rural hamlet. Her parents are poor and only have a basic education. The main family livelihood is the household plot. Additional income is made through tricycle-based deliveries. Xiao Zhen is not school-age but she finds it upsetting to see her sister attending school with other children: the family's home is situated only yards from the hamlet school.

Xiao Zhen's mother does not know whether her daughter will be able to go to school or whether the family's financial circumstances will permit any form of special education. It is hard enough finding the money for books for the elder daughter (who does not have impairment).

Almost all the farm work is done by Xiao Zhen's mother. Xiao Zhen's father is seldom at home. Xiao Zhen's mother says "he has never bothered with his daughters". Xiao Zhen's mother blames herself for her daughter's deafness [which resulted from misused antibiotics to cure a fever, see Alison Callaway's paper in this book]. Xiao Zhen's parents took her to Shanlin County Hospital and were told that the condition was incurable. A hospital in Nanjing told them the same thing. Shortly after, Xiao Zhen's father caught tuberculosis, so the family had no more money to spend on Xiao Zhen.

Recently, Xiao Zhen's mother saw a programme on television about a hospital in Hefei which claimed good results in curing deafness. So she plans to sell their grain and use the money to take her daughter to Hefei to see doctors there. "Whatever hospital I've taken her to, the results haven't been good - I am always making inquiries and wanting to find out about somewhere good to take her for an examination ... all that I want it to cure my daughter's illness".

(Research Notes from a semi-structured interview with the Zhen household, Shanlin County Research Project, Anhui Province, Data Code TZCD-5, Nov 1996.)

### **Xiao Guo's Family**

Xiao Guo got a fever in infancy. After he recovered, his family discovered that his legs were weak and he could not walk or stand up. Xiao Guo's parents sought help from the local doctor, and the doctor discovered that he probably had polio. The doctor advised that they go to the county hospital, where the diagnosis was confirmed. Then they went to a hospital for infectious diseases in Tianjin City. The expenses - both medical and residential - were huge. So, they sold their own house - a four-roomed house - to cover what they owed in medical expenses. They had built their house for 1500 yuan but could only sell it for 1600 yuan, so they went to the county bank and took out a loan; the government provided some assistance. They still owe 3000 yuan. Xiao Guo's father is self-employed in fish rearing. Xiao Guo's mother stays at home to look after Xiao Guo, and she also farms the household plot. The family now live in a one-room house.

(Research Notes from a visit to the Guo family home, Heping County Research Project, Tianjin Municipality, Transcript Code NH-13, April 1996.)

## **MAKING CONNECTIONS**

Everyone who reads this paper will probably have heard stories like those told by Xiao Guo's, Xiao Zhen's and Xiao Lin's parents, whether or not they have been to China. There is something in these stories that seems to ring true across many different cultures and countries. And yet...still there is something that ties them to China in the 1990s. The stories are the product of a complex interplay of different factors and processes, past and present, past refashioned into present, partly global yet indisputably Chinese.

In the sections that follow, I outline some of those factors and processes. The discussion is intentionally brief because my aim is to encourage others to make similar connections in their own areas, rather than provide a detailed analysis of disability in China (that is the subject of past and planned publications).

## **SOME STARTING POINTS**

What do the stories of Xiao Guo, Xiao Zhen and Xiao Lin's families tell us immediately?

- Parents revealed a high degree of care, commitment and concern for their child, irrespective of social or economic status - with the apparent exception of Xiao Zhen's father who seemed disinterested in his daughter.
- All the families had invested significant time, resources, energy and anxiety into seeking a cure for their child. Family members took on additional income generation, ploughed all their earnings into medical treatment and, in one case, incurred considerable indebtedness and sold a primary asset to meet medical costs.
- A large number of medical and rehabilitation professionals were consulted - in the local area, the nearest rural town, and much further afield (e.g. Shanghai). This was expensive, but was felt to be worthwhile to secure the best possible chance of a cure.

These starting points prompt further questions.

- Why is it so important to find a cure for a child's impairment, even to the

- extent of risking indebtedness for the entire household?
- Has it always been so important to find a cure? Is it more important now than in the past?
- Have families always made long journeys to access medical and rehabilitation services?
- Do family responses to impairment vary according to the child's gender?

In turn, these questions suggest avenues for further research, for example:

- Social and cultural views of impairment and people with impairments.
- Social and cultural views of the child (girl child, boy child), in relation to the family and notions of adulthood or personhood.
- Household expectations and household economic strategies.
- Concepts and availability of curative medicine and rehabilitation.

Add to this list the importance of exploring wider structures and changes in society, economy, policy and provision (local and national) - all of which will impact on the above (see also Momm & König 1989 for a useful framework for baseline studies).

When making connections, all these areas need to be considered in relation to each other, in combination, and with an eye to the past as well as the present. As this is done, a more complete story begins to emerge, one that is more closely woven into the particular social, cultural and structural fabric of China's villages in the 1990s.

## **THE BEGINNINGS OF A MORE CONNECTED STORY**

The starting points, questions and areas for further inquiry provide a good framework for contextualising the stories of Xiao Guo, Xiao Zhen and Xiao Lin's families. While space does not permit me to write my own version of a more connected story in any detail, it is probably helpful to fill out the framework (or parts of it) to give a feel for what this might entail.

### **Wider Socio-Economic Changes and their Impact on the Household**

China is one of several countries "in transition" - a term used to describe countries that were once aligned to a Communist bloc but are now engaged in capitalist or quasi-capitalist development. The notion of a country in transition is

helpful in so far as it reminds that China has abandoned certain structures, modes and ideologies of development that dominated from the 1950s to 1970s (rural collectives, mass movements, revolutionary struggle, barefoot doctors). Less helpfully, the notion of transition implies an active movement towards a clear destination. Yet, the sobering reality is that China might actually have arrived.

It is possible to see China as a (pretty big) microcosm of the world in the 1990s. The widening gap between the minority and majority worlds is played out within China's vast borders, between city and village, between coastal and inland provinces. For some people, China's new road to development has brought many opportunities - above all the chance to own and profit. For others, the dismantling of China's "iron rice bowl" (guaranteed, if basic, social security, employment, schooling and healthcare) has put their lives at risk. For most, the experience of China's economic reforms has been bitter-sweet. The loss of the iron-rice bowl means greater insecurity and expense; but this has been sweetened by the chance to make money, move around, and consume. Development in China is a double-edged sword.

Competition in the labour market is severe. Unemployment constitutes a very real threat to most households. The costs to the household of basic living, schooling and health care have sky-rocketed. After decades of "free" schooling and healthcare, families - including rural families - now have to pay fees. All of this makes for a more insecure environment in which to raise a family and run a household. It is also a more pressured environment, because the opportunities for families to make money and gain status are there, and everyone knows someone who has done well in the new China.

### **Family Perceptions of Impairment - Past into Present**

In China (and perhaps elsewhere), a new-born baby or child might usefully be conceptualised as "lineage capital" and "economic capital".

The notion of "lineage capital" harks back to the Chinese past, and enduring cultural and cosmological legacies that tied the body to familial and socio-cultural expectations. The expectations were from and for the whole family (including ancestors and unborn descendants), to be realised through individual family members and their fulfilment of core obligations. In the past, these obligations were: marriage, production of male children, correct performance of ancestral rituals, and provision for family elders. Through these, the individual

attained the socio-cultural status of personhood. The core obligations were broadly similar for men and women (although a woman would always have diminished personhood compared to a man). Key differences included the fact that a married woman's obligations were to her husband's family, not her own; and that a woman's full personhood depended (to a much greater extent than that of her husband) on bearing a son. Impairments were a threat to the fulfilment of family obligations, partly because of social and legal regulations that prevented people with certain impairments from participating in rituals or from getting married (and thereby having children).

In the 1990s, many of these obligations remain highly relevant to perceptions of and responses to childhood impairment. Moreover, some of them have been intensified through increased economic opportunities and insecurities. Enter the concept: "economic capital".

For the Guo, Zhen and Lin families, impairment potentially undermines the entire household's capacity for economic survival and longer-term security:

- loss of household labour if the individual is not or is not perceived to be "productive";
- loss of household labour if a "productive" family member becomes a "carer"; and
- sometimes exorbitant costs of medical care and cure seeking.

Arguably, the potential economic impact of impairment on the household is greater now than it has been since the creation of the People's Republic of China in 1949. Moreover, current public discourse in China is replete with references to ensuring that disabled people "become an asset to society instead of a liability" (CDPF 1988). The same perception shapes a household's response to impairment. Most families are prepared to invest heavily to prevent the anticipated economic hardship.

### **Available Support Systems and their Impact on the Household**

China's new road to economic development has also engendered the break-up of collective forms of social organisation. The non-kin and collective support systems established during the 1950s to 1970s have been eroded as work units and rural collectives have been progressively dismantled or sidelined under the socio-economic reorganisation spearheaded by Deng Xiaoping since 1978. Meanwhile, family support systems, which had been undermined by the

introduction of work units, neighbourhood committees and rural collectives, have been further weakened since the 1980s, as family size has decreased and internal migration has increased. There is little by way of a safety-net for those who have no neighbourhood-based or kin-based support systems. State-social welfare entitlements are wholly inadequate in much of China, especially in rural and remote areas. Where disability-related support is provided, it tends to be on an ad hoc basis, mostly to coincide with festivals and state holidays, rather than as a reliable weekly or monthly payment.

In this context, families are understandably concerned about their capacity to support a disabled family member, particularly as other family members get older and die.

### **Family Responses to Impairment: Prevention through Cure**

Prevention is a cure. Families invest time, resources and energy to educate, rehabilitate and ideally, cure their child. The bottom line is that the best guarantee of a good future - for the family as much as for the child - is perceived to be a cure.

The search for a cure is often expensive and protracted. Families may begin with a visit to a local doctor but cure-seeking seldom stops there. The poorest families journey to hospitals outside the county; more wealthy families travel further afield to Shanghai or Beijing. Even within the locality, a family will pay for an examination at the local county hospital in addition to visiting several different doctors and clinics in the area.

The hope for complete "recovery" (kangfu, sometimes mis/translated as "rehabilitation") and the long-standing nature of medical help-seeking in Chinese cultures (Kleinman et al 1975, Kleinman 1980) protract the search for a cure, even when informed that a condition is incurable. The situation is made more complicated by the multiplicity of health and therapeutic systems which form the Chinese medical landscape; and by the strong social expectations that doctor-swapping will probably be necessary, and that a family should never give up their search (see Kleinman et al 1975). A high degree of perseverance is expected which may ultimately work against the child's interests. Opportunities for schooling and social participation may be lost through time taken up by medical treatment, not to mention the impact on self-identity and esteem that protracted medical help-seeking may have. The search for a cure can also work against the household's long-term interests.

The costs of medical care (fees, treatment, travel and accommodation expenses, time out of everyday income generation) can be prohibitive and are borne almost exclusively by the families. Occasionally, a poor family might receive assistance from the government, or doctors and hospitals might agree to reduce fees. Household poverty does not automatically reduce the drive to find a cure, since a cure is seen as a way of avoiding perennial poverty for the whole household. Further indebtedness in such circumstances is not uncommon.

### **Additional Pressures: The "One-Child Policy"**

The fear of indebtedness often diminishes in the face of additional pressures that bear down on parents, especially mothers. Some of the heaviest pressures are related to what might be called a "cult of the perfect child", which has swept through China on the back of the one-child policy and which articulates with the enduring social and cultural importance of having a long line of ancestors and descendants. (The phrase "one-child policy" is now inaccurate but is used here for convenience, see Davin 1990.)

There is no doubt that the 1980s and 1990s have been a boom-time for the child. Children have become the object of a massive consumer market. They have acquired the collective nickname of "Little Emperors". Moreover, given that most couples are expected to abide by a one-child policy, the onus on having a perfect (for which read healthy, intelligent, attractive, non-impaired) child is becoming even more intense. This pressure combines with already negative social attitudes towards impairment - related in part to the bleak prospects associated with impairment (less chance of marriage, employment, education, social status, etc.). The result is a context in which disabled fetuses are more likely to be aborted; disabled babies are more likely to be abandoned, often purposefully, at the door of Chinese hospitals and welfare institutions; and parents of disabled children do their utmost in search of a cure - even to the point of producing impairment (see Callaway in this book). Somewhat paradoxically, this situation has been exacerbated by growing disability awareness.

### **Additional Pressures: Disability Awareness**

The last two decades have also seen the formation of the China Disabled Persons Federation, the emergence of Deng Pufang (the late Deng Xiaoping's

eldest son, a wheelchair user) as its champion, and a range of top-down initiatives to challenge negative attitudes, change disabling language, and promote disabled people's participation in society (Stone 1996). In the 1990s, China's population is far more "disability-aware"; but disability awareness too has proved something of a double-edged sword.

The Chinese government and mass media have made significant steps forward in highlighting the poverty and discrimination that many disabled people and their families face. The government has called for an end to this through maximising the opportunities that disabled adults have to support themselves (via education, employment, rehabilitation, equal opportunities), and through minimising the perceived risk to the state and burden to society and families that disabled people might bring (via rigorous and well-publicised prevention strategies). Thus, there is a Law for Protection for Disabled People (1990), and there is also a (basically eugenic) Law on Maternal and Infant Health Care (1994).

Increased disability awareness might have fostered a more supportive environment for some disabled people, but it has also added to the already intense pressures on families with disabled children to seek a cure - to shield their child and themselves from disadvantage.

### **A Rehabilitation Business: Demand and Supply**

Increased disability awareness has also contributed to a boom in the rehabilitation business and health care generally. This has been apparent in China throughout the 1980s and 1990s, and constitutes a refashioning, if not an intensification, of long-standing interests in the body and health. "Traditional" Chinese medicine (a convenient but misleading term) has long had an interest in impairment - and many parents turn to Chinese medicine practitioners in their search for a cure. But western-style rehabilitation is also on the menu hailed within China as a "new" area of medicine, imported from the west.

The growth of a western-style rehabilitation industry in China has been spurred on by the rapid globalisation of the rehabilitation business, and the increased involvement of western and international professionals and organisations in promoting rehabilitation medicine and technology in the majority world. The fact that some of this outsider involvement may be welcomed and much-needed does not detract from the cumulative - and potentially counter-productive - impact that such involvement can have on family perceptions of and responses

to childhood impairment, let alone on disabled children's lives and identities.

Add to all this the innumerable television and radio programmes, popular magazines and tabloids which focus on healthcare, beauty, fitness, and also the identification and cure of "diseases". The popular magazine Health is one such example. It regularly features apparently legitimate (sometimes fraudulent) advertisements for western and Chinese medicine: Diabetes cure! Epilepsy cure! Mental illness cure! Deafness cure! Paralysis cure! And so on. Books targeted at families, especially parents, on common diseases, treatments and home-based rehabilitation are widely available and relatively cheap.

The rehabilitation industry in China may still be small but it is expanding rapidly, and its expansion is in no small measure attributable to growing grassroots demand from parents that want to do the best for their family.

## **Multiple Dimensions**

In addition to these overarching factors and processes, a parent's or family's perceptions of and responses to their child's impairment may vary widely according to the interplay of a host of different variables, including:

- Child's gender, age, type and severity of impairment.
- Parents' background: literacy, education, employment.
- The family's support networks: local and regional; kin-based and non-kin based; social contacts (e.g. local government, school); contact with disabled children and adults.
- The family's information networks: literacy, radio, television, telephone, internet; contact with relevant individuals, organisations or networks.
- Household assets: land, profitable sidelines, house, savings, access to credit.
- Household locality: rural, peri-urban, urban; proximity to services.

BUT, and this point cannot be made loud enough, the connections between these variables and specific outcomes are not always straightforward. For example, illiteracy will probably impact on the household's access to information, services and opportunities; but there is no simple correlation between parental illiteracy and neglect of a child (both Xiao Guo and Xiao Zhen had parents with very low levels of literacy). Similarly, evidence from China's orphanages points to the socio-cultural undesirability of a girl child with an

impairment (see for example articles in The Observer 1996), but by no means all disabled girl children are rejected by their families or within their families. Finally, poverty may reduce opportunities but it does not reduce the pressures on a parent to search for a cure or access "specialist" services.

## **TO SUMMARISE SO FAR**

Obviously, the above is just a taster of some of the connections that could be made to understand what has gone on "behind the scenes" of the three stories told by Chinese parents. It illustrates, I hope, that stories from the majority world demand and deserve careful analysis. In this way, a story ceases to be one that could have taken place anytime, anywhere.

Producing a more connected story deepens one's understanding of the pressures - past, present, social and economic, personal and public - that can inform the actions and beliefs of individual families. Only then does it become possible to listen properly and act appropriately. Research that makes connections has a much higher chance of producing useable knowledge - the kind of knowledge that will prevent outsiders from formulating inappropriate action plans. For example, the three stories from China's villages, and the wider connections that were made, raise many issues that need to be recognised because they would influence the process and outcome of any disability-related intervention.

- "Child-focused" interventions may conflict with the fact that a child exists in relation to her/his family, and that most family responses are ultimately family-focused.
- Gender as a variable in shaping a child's life chances.
- The intense pressures on families (mothers in particular) to search for a cure - at almost any cost, even when a condition is deemed "incurable".
- The likelihood that families will explore several different options at the same time (e.g. Chinese medicine and also western-style rehabilitation techniques).
- Information needs are huge; recognising also that any response to information needs will result in yet more leads that families feel bound to follow.

These are just a few pointers that spring to mind. But they are helpful because they set family demands in context. Parental suggestions for more high-tech

rehabilitative and curative services may be based less on the lack of such services in the region, and more on the costs of accessing existing services and/or the families' "failure" to find a cure.

## **STORIES FROM CHINA'S NEWSPAPERS**

From villages to newspapers ... and no doubt the use of Chinese newspaper stories in a "research paper" will raise eyebrows. After all, we are talking about a country known for severe restrictions on freedom of the press. What will raise eyebrows even more is that these stories set out the voices of Chinese disabled people who are dissatisfied with the way in which they have been treated because of their impairment.

The stories that follow are not at all representative of Chinese media outpourings on disability (even though both gained national coverage) or of actions taken by Chinese disabled people. Rather, they represent new undercurrents of change, the still small voices that are growing louder and demanding more.

The stories also challenge western ideas - about where to look for data, and about the nature of stories on disability in the majority world. For example, when people heard about my research, I got the following responses: "that must be depressing" (a Professor in East Asian Studies); "you don't see any disabled children, they're all in orphanages" (a final year student of Chinese, after a year in China); and "they practise eugenics" (an activist in Britain). There is some truth, but only partial truth, in these statements.

It is all too easy to slip into stereotypes and compound myths (see Kisanji 1995a, 1995b, Ingstad 1995 on western myths and constructions). Seeking out different stories and using different sources can be a helpful way of reminding yourself, and others, that little is straightforward, and that where there are people, there are forces for social change.

**“Why can't an ugly student go to university?” (*Beijing Youth Daily*, Oct. 1995)**

The story of Yang Hongwei is about a young man who moved successfully through the mainstream school system, gained high grades in final exams (in excess of the standard requirements of Chinese university entrance), applied to several universities but was rejected by all of them on the basis of an "ugly"

appearance.

Yang had encountered a certain amount of prejudice prior to that point, but had also been strongly supported by family members and local teachers, who urged him to apply for higher education. By all accounts, he was an exemplary pupil. However, even the appellation of "Three Good Student" did not stop universities from rejecting him:

the student's bodily impairment will cause difficulties for his study and therefore we will not accept him (Lanzhou University);

we have many activities and contacts with those outside the college, and we are afraid that admitting this kind of student would have a negative influence on these and on other students studies (Zengzhou University).

Faced with these rejections, Yang Hongwei complained to the local, provincial and national Education Commission and finally took the story to the press with the questions: "are universities in the business of education or aesthetics?" and "should you select on the basis of academic grades or external appearance?"

How far the story is a disability story is up for debate. On the one hand, "ugliness" does not slot easily into the restrictive, functionalist and five-fold definition of impairment that has been standardised in China since the 1980s. As a result, the local Disabled Persons Federation felt that Yang Hongwei was not, strictly speaking, a disabled person. However, the barriers faced by Yang Hongwei were clearly comparable to those faced by prospective students with state-defined impairments, and on that basis the local and provincial Disabled Persons Federations agreed to take up his cause.

As a result of Yang's media campaign, Yang was given offers by various universities around China, received a considerable number of letters of support and financial donations, and was offered the chance for free plastic surgery in a Beijing hospital and (according to some sources) in America. Yang redistributed the donations to students in hardship, put university on hold for a while, and took up the offer of plastic surgery in Beijing. His mother explained in a follow-up article in the Beijing Youth Daily (21 February 1996) that the chance for a more acceptable appearance could not be passed by since "after college, he will have to make his way in the world, get a job, make a life".

On the broader scene, the story opened debates on disabling barriers to

students with impairments and prompted at least one provincial Education Commission to co-opt someone from the provincial Disabled Persons Federation to act in cases where disabled students were rejected by universities on the basis of (state-defined) impairment.

**"Who will safeguard the legal rights of disabled people?" (*Legal Daily*, Feb. 1994)**

We are 77 disabled people from the city of Rui'an in Zhejiang Province.

This article is best described as an open letter, written by a group of disabled people to the Chinese public, in which general and specific grievances against macro- and micro-level injustices are set out with uncompromising clarity. The first few sentences of the letter describe the increased hardship and poverty faced by disabled people who (the letter states) have been severely disadvantaged by the economic reforms of the 1980s, increased economic competition and labour markets - particularly in rural areas. The letter continues to detail a series of specific incidences involving several disabled people in Rui'an and senior personnel of the Rui'an Municipal Traffic Police.

The incidents began following official decrees in June 1993 that registered disabled people could purchase a "welfare-vehicle" (fuliche; a three-wheeled motorbike with space for a backwards-facing passenger or goods) to use for mobility. After saving to get the money together, several disabled people were able to buy a welfare-vehicle. The following month, they went to the municipal traffic police to get the appropriate road licence, only to be flatly refused by the officer-in-charge on the basis that the vehicles bought were "not road-worthy, a pile of scrap". A number of disabled people, whose livelihoods and mobility depended on the vehicles, resorted to driving them without a licence. They were caught, detained, and their vehicles were smashed. On top of a fine, some were beaten whilst in custody. The letter claims that this type of incident happened over 70 times between July and the end of October 1993. It continues:

On 29th September, the aforesaid officer-in-charge mobilised the traffic police, intercepted and detained over 100 welfare-vehicles. On 4th October, he notified disabled people that they should go to collect their vehicles. He forced the disabled people to carry a signboard [gua paizi, a humiliating act associated with the Cultural Revolution], to sit on their vehicles and be photographed. Then, in front of a crowd, he insulted the disabled people. When they asked him to stop, the officer-in-charge of the

traffic police cursed them in front of everyone, saying: "You go home and ask your mothers why you were born a cripple".

Following this incident, the disabled people and disabled colleagues sought redress, sought someone who would take an interest in the case, but found no one. In the meantime, the officer-in-charge supplied licences to non-disabled people who used welfare-vehicles for personal profit. In the end, disabled people in Rui'an were given two options: to rent their licences for the exorbitant sum of 200-300 yuan per month, or not use their vehicles at all. The letter concludes:

We make a desperate cry to society: think hard about the appeal we are making as disabled people. Safeguard disabled people's legal rights, in accordance with the law, and quickly put a stop to the illegal behaviour of the officer-in-charge from Rui'an City Traffic Police.

I have no idea of the final outcome of the letter. I would suspect that, given recent anti-corruption campaigns, action was taken in favour of the disabled people of Rui'an.

## **LEARNING FROM LESS ORDINARY STORIES**

The fact that these stories are a) not representative of Chinese media images on disability, and b) describe actions that are not necessarily representative of China's disabled population writ large, need not detract from the invaluable insights they offer into the experience and construction of disability in China.

For starters, in these two stories, we learn about:

- Experiences of discrimination based on impairment, and indicative of "disability" as disadvantage and discrimination. Whilst the actions described may not be everyday occurrences, there is plenty of evidence from other sources that the experiences that prompted them are not so unusual.
- The difficulties of exercising rights that exist on paper (such as rights conferred through the State Council's "Regulations on Education for the Disabled", effective since 1994), balanced by the doors that are opened because such rights do, at least, exist on paper.
- An apparent alliance of interests between the highest levels of the Chinese state and the disabled people involved. The actions taken do not

constitute "political dissidence", since the appeal is for the realisation of rights that have been granted by the government and enshrined in state policy and legislation.

- The use (infrequent but increasing) of the Chinese media to turn up the volume on disabled people's own demands, to name and shame those who have denied them their rights, and to win public support to take on higher authorities and officials. (Incidentally, Yang Hongwei's story attracted international and internet attention, including anger from overseas Chinese students that Yang had been rejected by universities.)
- The restrictive definition of who is, and who is not, a "disabled person" and how definitions correspond to individual impairment rather than social barriers. Further research would reveal that state definitions of impairment have existed for centuries in China, but have also been influenced by the promotion of the World Health Organization International Classification of Impairment, Disability and Handicap (Stone 1999).
- The power of dominant and disabling constructions of "normality" (again, linked to state and socio-cultural definitions of normative bodies and behaviours, and intensified by the availability of medical and cosmetic techniques to "normalise" appearance and function).
- The reappearance of charity fundraising in China, after decades in which charity was denounced as western, capitalist and bourgeois. It is now no problem for people to donate to "good causes" and "disadvantaged individuals" such as Yang Hongwei.
- The emergence, in some places, of a shared identity as disabled people, who experience socio-economic disadvantage and negative attitudes based on their impairment.

Signs of a shared identity as disabled people may well be more evident among the privileged strata of China's disabled population: generally male, younger, with physical impairments often acquired in later life, with some education, some employment and some income, living in the cities. And yet, there is something very powerful when reading about the collective action of the 77 disabled people from Rui'an. Here, it is important to note that the China Disabled Persons Federation does not have a membership base and is therefore not an organisation of disabled people, although it is led by disabled people at the national executive level. This means that the action and solidarity of the 77 people from Rui'an occurred outside any state-sanctioned organised structure. That is not only exciting; it also puts the lie to those who would argue that disability movements are a creation of western politicised individuals.

These stories make for thought-provoking reading. They are at once inspiring and depressing. They bring out the everyday reality of disability as social disadvantage and oppression. But they also point to new, less usual but potentially significant undercurrents of change. Earlier, I said that the government's programme of raising disability awareness was a double-edged sword. I think these stories add an extra dimension to that statement. Top-down and state-led initiatives may have limited power to transform a disabling society (assuming - and one probably shouldn't - that such is the intention). But who's to say where this might lead, especially when individual voices become collective voices.

## **SOME POINTERS FOR STUDY AND RESEARCH**

Where do we look for understanding on disability in the majority world? How do we respond to the stories we find? Do we look for links between those stories and their broader contexts? Do we seek stories that challenge our own outsider assumptions?

### **Sources**

The best source on disability is disabled people themselves. The value and validity of listening to the voices of disabled people has become a central feature of much disability research in the UK (see Barnes & Mercer 1997, Clough & Barton 1998) and elsewhere (e.g. Coleridge 1993, Ingstad & Whyte 1995, Kisanji 1995).

There may also be other relevant sources. The range and nature of those sources will depend entirely on the specific area context. In some areas of the majority world, with a strong oral culture and tradition, there may be little to be gleaned from written material (see Sue Stubbs' paper in this book). In my own case, China has one of the longest and strongest traditions of written culture in the world. Language, text, inscriptions, proverbs; local and national government policies; novels and poetry written by or about disabled people; teaching manuals on education and rehabilitation; books on the sociology of disability; newspaper articles; dedicated disability magazines; brochures on disability initiatives, and so forth. None of which are particularly "easy" to analyse (you have to be very careful about how you use state propaganda, policies and statistics, for example); but all of which can offer insights and new angles.

At the end of the day, the search for understanding isn't really about what you get. It's about how you get it, how you use it, and how far you make the crucial connections.

## **Making Connections**

I've probably said enough on this already! I only hope that this paper encourages rather than deters prospective researchers on disability in the majority world.

The sheer range of possible connections that can be made is especially daunting given that the social study of disability in the majority world is still new. There's not much past research to fall back on - which means you will have to juggle between breadth and depth. All the more important, then, that you take the time to set up your own framework of possible variables, factors and processes. Not all majority world stories will be as complicated as stories from China - several decades of rapid social and structural change, a sudden conversion to western-style capitalism, and an equally sudden interest in disability from the highest echelons of the Chinese state. But I would suspect that the realities of disability in the majority world generally, especially in urban and peri-urban areas, are much more complicated than outsiders assume and that researchers have hitherto suggested.

A parting comment on drawing up research agendas: yes, look to culture and cosmology, "traditional" attitudes and responses - these are crucial. But don't neglect institutions and ideologies, local and national provision and policy, modes of production and structures of social organisation, the existence of old and new professions and interests. All of these - be they indigenous, imported or imposed - are part of disability in the majority world.

## **CONCLUSION**

Disability in China is a social issue; a cultural issue; a development issue. The lived experience and construction of disability cannot be divorced from the particular social, cultural and development context in which it is located. And that holds whether you live in Beijing or Bombay or Birmingham.

The implications of this for disability research and action in the majority world are far-reaching. In this paper, I have underlined the importance of "making connections" between individual stories and the wider contexts in which those

stories are situated, produced and find meaning. I have also pointed to the insights that can be gleaned from hunting out extraordinary, as well as everyday, stories and using a mix of sources.

None of these suggestions are new (that much is clear from many of the contributions to this book and other excellent texts on disability in majority and minority worlds). Yet still it demands to be said - not least because it remains the case that far too little attention is paid to the experience and construction of disability in the majority world, even less that recognises the complexity, changes and contradictions that characterise majority world realities.

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