Child disability policy in China: child and family experiences

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Outline

Research background and questions

Human rights framework

Right to life case study

Policy implications – social policy, children, disability

Resources and contact details
Research questions

Formal policy position
- profile of children with disabilities and their families
- welfare policy for children with disability

Family and child experiences of the children’s rights
- life, protection and care within a family
- economic security
- child development - access health services, disability support and education
- social participation
Human rights framework

Conceptual and legal

Children, disability, women, families

- Inter-relational experience of rights
- Relative to other children in their community

Legal and policy obligations

- China Law on the Protection of Disabled People 1990/2008
Methods

Second China National Sample Survey of Disability 2006, 10% sample – 1002 children

Fieldwork

- case study children and families (52) – observation, interviews and documents
- local officials, staff and managers
- media analysis of high profile cases
Children with disability in China

Distribution – 1.63% of children, higher rates for

- rural areas 1.77
- boys 1.78
- Poorer and inland areas – map

Most common disability type different to adults

- Children – intellectual, multiple and physical
- Adults – physical, hearing, multiple and vision
- Due to life stage; health care and support; and understandings about disability?
Proportion of children with disabilities <18 years by location
Right to life and protection – background

Decrease from 8-9 million to 5 million children with disabilities in 1986 to 2006. Possible reasons:

- improvements in medical services during prenatal and postnatal care
- abandoning babies with disabilities, including ceasing medical treatment
- failure to register the birth of babies with disabilities

Tens of thousands of children with disabilities, mainly very young babies, are recorded as abandoned by their parents every year.

Some become the responsibility of the state.

Unknown number of others die from a lack of care and protection.
# Five cases to analyse right to life

<table>
<thead>
<tr>
<th>Child</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Parent</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Niuniu</td>
<td>Girl</td>
<td>2</td>
<td>Zhou</td>
<td>Father Beijing city</td>
</tr>
<tr>
<td>Xing*</td>
<td>Boy</td>
<td>15</td>
<td>Wang*</td>
<td>Mother Fujian province, rural</td>
</tr>
<tr>
<td>Hope*</td>
<td>Girl</td>
<td>New born</td>
<td>Li*</td>
<td>Parents Tianjin city</td>
</tr>
<tr>
<td>Heng and He*</td>
<td>Boys</td>
<td>13</td>
<td>Han</td>
<td>Mother Guangdong province</td>
</tr>
<tr>
<td>Gao</td>
<td>Girl</td>
<td>3</td>
<td>Liu</td>
<td>Mother Jinmen city</td>
</tr>
</tbody>
</table>
Children’s right to life

- Niuniu born in Beijing in 1990. Her parents had higher education. She was blind from multiple retinoblastoma, which threatened her life. The doctor recommended surgical treatment, but because she would be blind and had a 50 per cent chance of the cancer recurring before she was aged 30 years, the parents decided not to proceed with the treatment. She died aged nineteen months.

- Xing. Informed of the boy's disabilities, his father's extended family, wanted to abandon him. His mother took responsibility to support him. At the time of the fieldwork, he was aged 15 years.

- Hope born in 2010 in Tianjin with disabilities. Her parents decided against surgery, sent her to a hospice and refused NGO assistance to save her life.
Children’s right to life

- Heng and He, thirteen-year-old twins, with cerebral palsy in Guangdong. Their mother, Han, killed them and attempted suicide. She was sentenced to five years imprisonment.

- Gao girl born with a heart condition and the family was struggling to save money for the operation. When she was aged 3 years, Gao fell on a shopping centre elevator, breaking her right hand and became permanently disabled. Her mother stabbed her to death and attempted suicide, sentenced 10 years in prison.
Right to life analysis

Right to life of children with disabilities was not fully protected

Throughout their childhood, their right to life was questioned

Whether to allow their children to die was a private decision

- State did not intervene
- Role of the professionals was about medical treatment rather than whether the child should live
- State only intervened after the two direct cases of infanticide of older children

Decisions remain a private responsibility, but protecting the lives of children with disabilities is also becoming a concern in public media.
Social policy implications

Many gaps in welfare provision to families of children with disabilities

Gaps are likely to be addressed over time in the context of

- economic growth
- development of a welfare system across the country
- emerging child welfare system with comprehensive support and services
Social policy reform

Significant policy reform is needed

• Policy change – new policies fill in policy gaps and to improve ineffective support to families of children with disabilities

• Policy implementation to create and share good practice is now a focus

• Promoting a social consensus about social inclusion to create a harmonious environment for people and children with disabilities
Policy – right to care and protection

Case study – no effective policy to protect life of children with disabilities in China

- death or life of children with disabilities almost entirely depended on the attitude and decisions of parents
- parents are not well supported in that process

Social and legal interventions to change the attitudes towards people with disabilities

- of medical professionals and community members
- necessary to overcome barrier to protect the right to life
Policy – right to economic security

Families more likely to be in relative and absolute poverty

Central government policies to address poverty but

- implementation limited by local government resources and attitudes
- should more effectively implement policy to improve the economic situation of families of children with disabilities
Policy – health and disability care

Universal free access to early medical intervention and therapy for children born with disabilities are urgently needed

- to minimise impact on their other rights
- families not forced further into poverty when they try to find and pay for support

Chinese government has policies to establish universal systems of health care to children with disabilities in China

- Coverage of medical insurance is expanding
Policy – education

China has universal free education policy, inclusive of children with disabilities. Policy relies on three strategies

- learning in regular classrooms
- special education
- home education

In practice, children are excluded because of the lack of school resources, facilities, training and a performance measurement system based on test results

Experience of children and families is that inclusive education policy implementation depends on local resources and attitudes
Policy – social participation

Discrimination against children with disabilities is expressly prohibited by Chinese law but

- without formal support for families, children at risk of serious neglect and a lifetime of social exclusion

Implication for policy development is combination of

- support for families
- access to mainstream services
- specialist support

for children with disabilities to experience rights equal to other Chinese children
Resources


China policy and disability policy research

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