

FACULTEIT LETTEREN  
TAAL- EN REGIOSTUDIES



KATHOLIEKE  
UNIVERSITEIT  
LEUVEN

## **LONELY CHILD OR TREASURE WANDERING AMONG THE STARS?**

Autism in China Through a Case Study of the Xingxingyu Education Institute

Promotor : Prof. Dr. N. Standaert

Verhandeling aangeboden tot het verkrijgen van de graad  
van licentiaat in de Sinologie door :

**Cindy De Clerck**

## **Acknowledgments**

I would like to use this space to express my gratitude to some people. First, I would like to thank my promoter, prof. Standaert, for the answers on many questions, for the interest he showed in my research, and for suggestions on the different chapters. Further, it has to be made clear that a thesis like mine, without much scientific literature to base myself on, cannot be realised without the goodwill of some people. In this regard, I would like to thank Stijn Deklerck for his help with preparing my research, introducing me to certain people, as well as for the suggestions he made on my writings. Also, I would like to thank Helen McCabe for answering my questions, and sending me some helpful articles. Although more recently, I also have to mention Elaine Clark for the insights she gave me through our conversations by e-mail.

Apart from that, I would like to thank everybody at Xingxingyu for their cooperation and hospitality. I express my gratitude to Tian Huiping who agreed on my coming, allowed me to take a closer look at very interesting information, and made some basic suggestions on my research. Also, I am grateful to Wang Peipei and Sun Zhongkai who clarified some lessons and arranged meetings. I also thank Wu Liangsheng, Deng Xiaoling, and Xie Yuqin to allow me to trouble them with interviews and questions, and Liu Wei, who allowed me to participate in her class and to conduct an interview with her. In addition, I thank all the other personnel at Xingxingyu to help me when necessary, to show interest in my research, and to show up during my English classes. But my sincere gratitude especially goes out to all the parents at Xingxingyu, who were willing to participate in my research in one way or another. I will certainly never forget anyone of you and I wish you all the best for the future!

To help me overcome the English language, I thank Cédric Vyvey, Claudia Lubk, Marnix Groot and Eamon Connell. To help me overcome some autism related problems, I thank Dora Vargasabjan. For making this thesis more comprehensible I have to mention Yasmina Youjil and Frans Giele. To help me overcome the obstacles that came my way during my education, I thank my classmates and all the teachers of our department.

## **Table of Contents**

<b>1. Introduction</b>	<b>p. 5</b>
------------------------	-------------

<b>2. Method</b>	<b>p. 6</b>
------------------	-------------

2.1 Interviews	p. 6
----------------	------

2.2 Observations	p. 7
------------------	------

2.3 Other Kinds of Material	p. 8
-----------------------------	------

2.4 Limitations	p. 9
-----------------	------

## **PART I: THEORETICAL FRAMEWORK**

<b>3. Autism</b>	<b>p. 10</b>
------------------	--------------

3.1 History	p. 11
-------------	-------

3.2 Current Situation	p. 12
-----------------------	-------

3.2.1 Some Statistics	p. 12
-----------------------	-------

3.2.2 Causes	p. 12
--------------	-------

3.2.3 Diagnosis	p. 13
-----------------	-------

3.2.3.1 Features Necessary to Diagnose Autism	p. 13
---	-------

3.2.3.2 Secondary Symptoms	p. 15
----------------------------	-------

3.3 Growing Up	p. 15
----------------	-------

3.4 Intervention Programs	p. 16
---------------------------	-------

3.4.1 Applied Behavior Analysis (ABA)	p. 16
---------------------------------------	-------

3.4.1.1 Main Characteristics	p. 17
------------------------------	-------

3.5 Autistic Families	p. 18
-----------------------	-------

<b>4. Autism in China</b>	<b>p. 19</b>
---------------------------	--------------

4.1 History	p. 20
-------------	-------

4.2 Current Situation	p. 22
-----------------------	-------

4.2.1 Some Statistics	p. 22
-----------------------	-------

4.2.2 Diagnosis	p. 22
-----------------	-------

4.2.2.1 Diagnostic Manuals	p. 23
----------------------------	-------

4.2.2.2 Diagnostic Instruments	p. 23
--------------------------------	-------

4.2.2.3 Problems	p. 23
------------------	-------

4.3 Intervention Programs	p. 25
---------------------------	-------

4.3.1 Traditional Chinese Medicine	p. 25
------------------------------------	-------

4.3.2	Therapies	p. 26
4.4	Growing Up	p. 26
4.5	Autistic Families	p. 27
4.6	Autism and Chinese Society	p. 27
4.6.1	Intolerance	p. 28
4.6.2	Tolerance	p. 29
4.6.3	Conclusion	p. 31
<b>5.</b>	<b>Providing Education for Autistic Chinese</b>	<b>p. 31</b>
5.1	Special Schools	p. 33
5.1.1	In Theory	p. 33
5.1.2	In Practice	p. 34
5.2	Normal Schools	p. 35
5.2.1	In Theory	p. 35
5.2.2	In Practice	p. 37
5.3	Conclusion	p. 39

## **PART II: CASE STUDY**

<b>6.</b>	<b>Early Intervention Plans</b>	<b>p. 40</b>
6.1	Non-Governmental Training Institutes	p. 41
6.1.1	Major Tendencies	p. 41
6.2	Case Study: Beijing Xingxingyu jiaoyu yanjiusuo	p. 43
6.2.1	History and Current Situation	p. 43
6.2.2	Classes	p. 45
6.2.3	Teachers	p. 48
6.2.4	Parents	p. 48
6.2.5	Children	p. 50
<b>7.</b>	<b>The Chinese Autistic Family: Focus on the Parent-Child Relation</b>	<b>p. 50</b>
7.1	Background	p. 52
7.1.1	Society	p. 52
7.1.2	Thoughts About Parenting	p. 52
7.1.3	Xingxingyu	p. 54
7.1.4	Family	p. 55

7.2	Parent-Child Relation	p. 56
7.2.1	Process	p. 57
7.2.1.1	Step 1: Awaiting the Diagnosis	p. 57
7.2.1.2	Step 2: Facing the Facts	p. 58
7.2.1.3	Step 3: Accepting the Child	p. 59
7.2.2	Two Examples	p. 61
7.2.2.1	Pan Xiang	p. 61
7.2.2.2	Li Jiaxun	p. 65
7.2.2.3	The Parents In Between	p. 68
<b>8.</b>	<b>Conclusion</b>	<b>p. 70</b>
8.1	Autism	p. 70
8.2	Autism in China	p. 70
8.2.1	Education	p. 71
8.2.2	The Parent-Child Relation	p. 72
8.3	A Personal Note	p. 72
	Appendices	p. 73
1.	Details of the Interviews	p. 73
2.	List of Hospitals Able to Provide a Formal Diagnosis	p. 75
3.	List of Institutes Connected to Xingxingyu	p. 77
	Bibliography	p. 81

## **1. Introduction**

The topic autism has recently received an increasing amount of attention. Specialists and outsiders learned more about this particular disorder, and the number of publications on the topic is rising. Still, this attention is almost exclusively confined to the West. There is remarkably less knowledge about autism cases in countries like China.

Given my long interest in autism and China, choosing a topic for this thesis seemed obvious. That is why I wrote it with great enthusiasm. Indeed, doing research on this topic, observing and participating in a NGO in China, conducting interviews, and finally writing this thesis, were all very interesting to me. I learned a great deal about autism and China, and probably had to change my views on both. I sincerely hope that the reader will find it as interesting to read as I enjoyed writing it.

In this entire thesis there will be two basic concerns, which will both be addressed in a specific way. The first concern is the reaction of society on autism. A first part of this thesis is based on this concern, although it is not omitted from the second part. To get an insight in how autism is regarded in society, there are many possible starting points. Here, it was chosen to take a closer look at education, and how autistic individuals and their families are treated in this regard. The first part of this thesis thus mainly concerns autism - both in China and the West - and education for autistic Chinese. Since education will be dealt with in scrutiny, special and normal forms will both be discussed, as well as early intervention plans.

The second concern is how autism is regarded within the family, especially by parents. The second part will deal with this topic. To study the parent-child relation, it was necessary to have a certain setting in which these parents could be interviewed and observed, for it is not possible to choose parents at random. Therefore, a case study was conducted at Xingxingyu 星星雨, one of the first NGO's in China to help autistic children and their parents. One chapter is devoted to this NGO, describing its history and organization. Another chapter provides some concrete autism cases, preceded by an explanation on some basic elements observed in these parents.

Although these two parts seem to be rather distinct, it is important to notice the link between them. Parents are imbedded in a society that has its specific thoughts on disability, but they also act as advocates to improve their situation, e.g. to make more autistic children receive education. Therefore, there is an interaction between society and autistic families that is visible in both parts of this thesis. In a conclusive chapter both parts will be discussed together, in an attempt to signify this interaction.

## **2. Method**

Since there is hardly any scientific literature about autism in China, it was necessary to collect information on the spot. During September 2005, a research period of four weeks was conducted at the youth department of the Stars and Rain Education Institute for Autism (Xingxingyu). During these four weeks, the researcher was a ‘participant observer’ at Xingxingyu, fulfilling a determined task in the organization while observing what was happening.

This institute was chosen because of its long history compared to other institutes, and because it seemed to have a prominent position among the families struck by autism in China. The youth department was chosen because these children all were six years or older, and therefore it was estimated that the parents were more experienced.

At that moment, 32 families were attending this department. After being introduced to the researcher, they all received a letter with some basic information about the research. They were asked to fill in whether they were willing to cooperate and to be interviewed. Also, they were asked whether the proper name of their child could be used in this thesis<sup>1</sup>. This letter was written in Chinese.

To present a general view of the way in which the research was conducted, below both the interviews and the observations made will be discussed. Because not all sources were used in every chapter of this thesis, in every chapter the specific material used will be pointed out. It also has to be emphasised that this is a qualitative study and thus this study does not necessarily resemble the overall situation of autism cases in China.

### **2.1 Interviews<sup>2</sup>**

16 out of the 32 parents addressed agreed on being interviewed. Among them there were four parents who were accompanied by another adult, being their partner or a home tutor. The interviews were always conducted one on one. In total, fourteen mothers and two fathers were interviewed, one parent out of every participating family. Their children were all between six and twelve years old, and in total there were three girls and thirteen boys. All children were attending three of the four classes organised by the youth department, being the development class, the class for children with better abilities, and the class for children with mediate abilities. None of the parents of the class for children with lesser abilities agreed on being interviewed.

---

<sup>1</sup> For those who did not want their real name to be used, an alternative name was chosen.

<sup>2</sup> For more details, see: Appendices, 1.

Except for four interviews that were conducted during classes, all the interviews were conducted in the evening, beginning from the second week of the research period. All the interviews were semi-structured in-depth interviews, set on one hour. They were all taped with a dictaphone, except for three parents, who did not agreed on being recorded.

During the interviews, parents were asked to describe the development of their child as seen by themselves and their environment. During the conversation, the researcher was particularly interested in the relation between parent and child, and how people in their environment (family, relatives, strangers,...) saw the autistic family. Every interview had a moment at the end where parents were encouraged to ask questions to the interviewer. These moments were off-tape.

After these sixteen interviews were conducted, the teachers of the youth department were interviewed. These four teachers were working at Xingxingyu for different periods of time, differing from almost two to eight years. Again, these in-depth interviews were semi-structured and set on one hour. All the interviews were taped, and during the interviews the main topics were the way parents saw their child, how this changed while attending Xingxingyu, and how society reacted on autism.

The last interview was with the principal of Xingxingyu. Again, this interview was set on one hour and taped, with only two main topics, being society and parents.

Every interview was conducted in Chinese.

The order in which these interviews were conducted was chosen for a reason. Being aware of the fact that parents have a more personal story to tell, it was chosen to first listen to these stories and afterwards ask principal and teachers for more general views.

## 2.2 Observations

Five of the parents interviewed were studied more closely. They all attended one class and were observed for four weeks. This class was not chosen for a particular reason, but the researcher was assigned to this class by the staff of Xingxingyu. During these four weeks the researcher attended most of the classes, and while observing, helped teacher and parents conduct their particular tasks.

This observation period allowed the researcher to study some families in more detail, to become closer to them, and to study the parent-child relation on a different level. Interviews showed that it was not always easy for parents to talk about their child's disability and about their own ways of conduct. While participating in class, the parent-child relation became more apparent. Also, through observing, the training methods used in the institute



became clearer. When necessary, the help of the teacher was asked to clarify a parent's behavior or a specific technique used.

During breaks and after school, informal chats were made with teachers, staff, parents, and volunteers. These chats were always written down afterwards and, since everyone was informed about the researcher's stay at Xingxingyu, these reports are also used in this thesis. A distinction between the interviews and the informal chats will be made by adding 'personal communication' whenever the latter is used.

### 2.3 Other Kinds of Material

During the research period, the principal allowed the researcher to look through all the newsletters published by the institute. Newsletters often contain letters from parents and teachers, information about parental meetings or society. They also contain information about therapies and training methods. Especially the letters by teachers and parents, and the information about meetings and society interested the researcher. Those articles were copied.

Also, the researcher was allowed to read the parental essays written by 22 parents whom previously attended Xingxingyu. These bundles were chosen at random. All the essays were read while staying at Xingxingyu and, on every essay, a report was written.

Those essays are weekly assignments wherein parents are asked to elaborate on a specific topic. The topics are as follows:

1. Development of the child.
2. Lovable qualities of the child.
3. Experiences of the parent's mood in interaction with the child.
4. Effective reinforcements used on the child.
5. Circumstances in which the parent reinforces the child.
6. Methods of prompting used.
7. The importance of prompting for children's learning.
8. The use of prompts in daily life.
9. Task analysis of a task set by the teacher.
10. The parent's impressions after attending Xingxingyu.

The information obtained from those essays is also used, but the names of the parents are not revealed, as asked by Xingxingyu.

## 2.4 Limitations

Conducting only one month of research has its limitations. Before the research started, parents already attended four weeks of lessons. This means that parents had already gone through some changes that the researcher did not observe. Because of this, principal and teachers were questioned on the behavior of parents, beginning with their arrival. Principal and teachers were also questioned about the behavior of parents after the eighth week of the semester, since this was when the research ended.

Because of this limitation in time, interviews had to start almost immediately upon the beginning of the research, without giving the parents a proper chance to get to know the researcher. This was not felt as a disadvantage during interviews, but it was observed that parents were more willing to have informal chats after the second week of the research.

Also because this limitation, there was not so much time between the first observation and starting the interviews. This had the disadvantage of the researcher still having to get used to the basic structure of the institute, while conducting the first interviews. Since there had already been a meeting with the staff of Xingxingyu before the research started, and since the researcher had already read through some material about Xingxingyu, this disadvantage was minimal. Obscure elements were clarified by the staff of Xingxingyu.

## **PART I: THEORETICAL FRAMEWORK**

### **3. Autism**

In the West, there is recently given an increasing amount of attention to the disorder autism. Not only do researchers devote more time on the topic, the public also became more aware of this particular disability. Movies like *Rain Man* have drawn the public's attention. Unfortunately, they present a rather narrow picture of what autism is, and what it means to be autistic. They do not necessarily give the public wrong information, but not every autistic person can count every match that fell out of a box with one glimpse of the eye (scene from *Rain Man*). Therefore, this chapter presents a general introduction on autism, based on Western sources.

In contradiction to the other topics dealt with in this thesis, a lot has been written on autism in the West. This information falls apart into three categories. Firstly, there are the publications by researchers, e.g. psychologists, neurologists and others. Their writings give us an understanding of what autism is. They describe the symptoms, the possible causes, and the methods of treatment.

Secondly, there has been an increasing amount of parents who wrote books to give the public an idea how it is to raise an autistic child. These people are often called the real specialists on autism, dealing with their child every day. Their stories give us a first glimpse of what autism actually contains.

Thirdly, individuals like Donna Williams, Gunilla Gerland, Dominique Dumortier and others wrote down their personal stories. These individuals all have a disorder in the autism spectrum, and their stories offer us a unique inside in what it means to be autistic. Because of their personal stories, the reader not only has to get rid of some prejudices, he/she also gets a more thorough understanding of autism. The emphasis in these stories is put on how to survive with this kind of disorder.

Together, this literature offers us a broad understanding of what autism is. This chapter will use all of the types of sources available. Scientific literature will be used to formulate some facts - like the history of autism, the features that are used for diagnosis - or assumptions, like the possible causes. Sometimes, the stories written by parents or autistic individuals will be used to exemplify the matter.

This chapter is written to give the reader some general information about topics that will be discussed later in this thesis. This is why some topics like Applied Behavior Analysis (ABA) and 'autistic families' are also addressed. No attempt is made to write a complete

guide about autism. The reader will be recommended to other writings for more information about topics partially addressed.

### 3.1 History

The term autism originates from the Greek word *autos*, which means ‘self’. The term was first introduced by the psychiatrist Eugen Bleuler in 1911, to describe a certain disturbance in schizophrenia. Autism meant that patients narrowed their relationships to people in such a way they excluded everybody except their personal selves.<sup>3</sup> The first reports on children with the disorder autism were, however, published in 1943 and 1944.

In 1943, Leo Kanner - a child psychiatrist - reported 11 cases of children he called autistic. He indicated a variety of individual differences, but also two cardinal features he thought were sufficient to diagnose a child as being autistic. The first feature was called ‘autistic aloneness’, referring to a psychological state of being isolated. The second feature was called ‘obsessive insistence on sameness’, referring to repetitive behavior, routines and other ways of conduct as seen in these children.

Kanner thought the cause of autism to be a social-environmental one. He explained autism as a disorder caused by a lack of maternal affinity. Although an accepted theory at that time, this theory is recently considered out-of-date. Despite this theory, the reports by Kanner are still frequently quoted, and the Kanner-syndrome was soon called ‘infantile autism’ or simply ‘autism’.<sup>4</sup>

Independently of Kanner, Hans Asperger published a German account of the same disorder in 1944. Due to the fact that he described a broader variety of children, including children that could be considered almost normal, the disability he described has later been called Asperger’s Syndrome. Nowadays, this syndrome refers to a subcategory of autistic children who have a normal or supernormal intelligence, and do not show any language impairments. Children who have Asperger do show some impairment on the social level, and show repetitive and routine behavior.<sup>5</sup> Discussions about whether there is any difference between this syndrome and high functioning autism are held, but, following the examples of Frith<sup>6</sup> and Whitman<sup>7</sup>, the term autism will be used in this thesis to refer to any disorder in the autism spectrum.

---

<sup>3</sup> Frith (1989), p. 7.

<sup>4</sup> Vermeulen (2002), p. 9; Frith (1989), pp. 7-11.

<sup>5</sup> Frith (1989), pp. 7-8; Whitman (2004), p. 25.

<sup>6</sup> Frith (1989), p. 8.

<sup>7</sup> Whitman (2004), p. 25.

## 3.2 Current Situation

### **3.2.1 Some Statistics**

At present, autism is considered a pervasive developmental disorder<sup>8</sup> that has its offset during the first 36 months of a child's life. Being a pervasive developmental disorder, autism does not stop the development but slows it down and causes life long damage. Also, since the development of the child is not completely stopped, the disorder can take on different forms during a child's life. Some behavior may disappear, while other behavior may start to show. This is one reason why defining autism is hard and why the term 'disorder in the autism spectrum' is used.

The term spectrum also points to the fact that children with a lot of different abilities can be autistic. Some 75% of all autistic children are said to be mentally retarded in addition to their autism<sup>9</sup>, so the other group is said to have a normal or high IQ<sup>10</sup>. Obviously, these two groups show different abilities, but all of them show some basic impairments<sup>11</sup>, which will be described when addressing the diagnosis of autism.

In total, an average of 60/10 000 children have a disorder in the autism spectrum.<sup>12</sup> Boys are more likely to be autistic, as for every autistic girl there are 3-4 autistic boys. Statistically, an autistic girl has a higher chance of having a more severe form of autism.<sup>13</sup>

### **3.2.2 Causes**

Many theories have been proposed as to what causes autism. These theories are either social-environmental, psychological, or biological<sup>14</sup>. Recently, there has been some agreement on the fact that autism is caused by some malfunction or deficit in the brain<sup>15</sup>. What causes this malfunction or deficit is unknown at present. Some studies, however, indicate that autism is highly heritable. Studies with identical twins, for instance, show that if one member has a disorder in the autism spectrum, the other child has a 60% possibility to be autistic as well.

---

<sup>8</sup> Other pervasive developmental disorders include: Rett's Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder -Not Otherwise Specified (PDD-NOS). For an introduction on these disorders, see: Whitman (2004), pp. 23-26.

<sup>9</sup> Although other studies show remarkably different results. A study in southeast England, for instance, showed this rate to only be 35%. Still, the 75% is widely reported. Frith (2003), p. 174.

<sup>10</sup> More on autism and IQ, see: Frith (2003), pp. 173-191.

<sup>11</sup> Whitman (2004), p. 27.

<sup>12</sup> Frith (2003), p. 85.

<sup>13</sup> Whitman (2004), pp. 45-46.

<sup>14</sup> For a review and recommendation of literature on possible theories, see: Whitman (2004), pp. 101-143.

<sup>15</sup> More on autism and the working of the brain, see: Frith (2003), pp. 228-254.

These studies, together with sibling and family studies, point out that autism could have a genetic origin. What kinds of genes cause autism is unknown at present.<sup>16</sup>

Since there is no cause found yet, there is no possibility of finding a cure. What is possible now is to diagnose the disorder. When the diagnosis is made, a whole range of therapies can be considered. In the next part, diagnostic features, as well as secondary symptoms will be discussed. Next, some attention will be given to therapies, with a focus on ABA.

### 3.2.3 Diagnosis

The two cardinal features presented by Kanner are not solely used to diagnose autism anymore. This does not mean that they are no longer considered as symptoms of autism, but recently the diagnosis of autism is broadened. To be diagnosed autistic, a person must show an impairment on the level of social interaction, communication, and patterns of behavior, as described in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) published by the American Psychiatric Association in 1994<sup>17</sup>. In order to be diagnosed autistic, there has to be a deficit in every category, from infancy on<sup>18</sup>. Below, some attention will be given to every category of impairment.

To diagnose a child with autism, two kinds of diagnostic instruments are used. A specialist, who is trained to observe the impairments defined to be present in the case of autism, can observe the child. Also, parents or caregivers who have thorough understanding of the child could be questioned. At present, a number of checklists are available, but interviews are also possible in this regard.<sup>19</sup>

#### 3.2.3.1 Features Necessary To Diagnose Autism

**Social Interaction**<sup>20</sup>: It is a misunderstanding that autistic people are not willing to have any social relationships. On the contrary, they are sometimes longing for social relationships as much as other people do, as becomes evident from stories like that of Dominique Dumortier<sup>21</sup>. The problem is situated in the quality of social relations. In small

---

<sup>16</sup> Whitman (2004), pp. 119-120.

<sup>17</sup> Other definitions of autism than presented in the DSM-IV might be used as well, but it is beyond the scope of this thesis to discuss them all. Only the DSM-IV is important to mention here. Furthermore, the basic impairments as explained in other definitions are similar to that in the DSM-IV. Whitman (2004), pp. 22-23.

<sup>18</sup> Frith (1989), pp. 61-62.

<sup>19</sup> Whitman (2004), pp. 35-38.

<sup>20</sup> More on social interaction, see: Frith (1989), pp. 136-155; Whitman (2004), pp. 75-83; Vermeulen (2002), pp. 18-20.

<sup>21</sup> Dumortier (2002), pp. 97-99.

children it might be observed that they do not make any eye contact or do not share experiences. When growing up, those problems stay observable.

Also, it appears very hard for an autistic person to understand social codes. They cannot understand why some ways of conduct are tolerated in one situation, but not in another, and it is hard for them to know how they need to behave. Tim describes his problems with the concept of shaking hands. He does not seem to know when to shake hands, how long it has to last, and how powerful the handshake has to be.<sup>22</sup>

**Communication<sup>23</sup>:** Typical for autism is that the development of language is delayed, referring to either verbal or non-verbal language<sup>24</sup>. This means younger children do not talk nor make any gestures to make their needs clear. When language finally sets in, communicating appears difficult. ‘Autistic language’ is typified by, for instance, repetitive use of words or echolalia. Another characteristic is idiosyncratic remarks. This refers to associations made between a word and an object, that are hardly understandable for other people. For instance, Uta Frith describes Paul who would refer to a saucepan as ‘Peter, Peter, pumpkin eater’. His mother had sung this nursery rhyme one day while holding a saucepan, so Paul had associated this particular rhyme with a saucepan.<sup>25</sup>

Problems in language are very often on the level of pragmatics, and even when a person can develop a rather normal way of talking, pragmatics often stays problematic. When the teacher said to Ben: “I am Elke, and you?” Ben replied: “I am not!”<sup>26</sup> Ben had not understood that this question actually meant: “What is your name?”

**Repetitive Behavior<sup>27</sup>:** Parents often report that their child is not able to play and that it is fixated on certain features of a particular toy, for instance the wheels of a car. This fixation on one part of a toy is included in the DSM-IV as one of the characteristics of repetitive behavior. Others are repetitive and stereotyped motor movements like hand flapping. Also included are fixations that are abnormal in focus or intensity. Thomas, for instance, is very interested in public transportation and will probably know all the lines and

---

<sup>22</sup> Landschip & Modderman (2004), p. 163.

<sup>23</sup> More on communication, see: Frith (1989), pp. 118-135; Whitman (2004), pp. 83-86; Vermeulen (2002), pp. 21-23; De Clercq (2005), pp. 67-145.

<sup>24</sup> Whitman (2004), p. 23.

<sup>25</sup> Frith (1989), p. 125.

<sup>26</sup> Vermeulen (2002), p. 22.

<sup>27</sup> More on repetitive behavior, see: Whitman (2004), pp. 87-90; Vermeulen (2002), pp. 24-27; De Clercq (2005), pp. 13-64.

their stops by heart. In addition, he cannot stop talking about them.<sup>28</sup> Gunilla Gerland was fixed on curved objects, and had to touch every curved object she saw<sup>29</sup>. Repetitive behavior can lead to routines that have no meaning for the outside world, but have to be executed by the autistic individual, as can also be read in the autobiography of Gunilla Gerland.

### 3.2.3.2 Secondary Symptoms

Besides three basic impairments, there are other symptoms that also seem to be present in some autistic individuals. Such symptoms are, for instance, sensory processing problems, motor dysfunctions, attention difficulties, displaying a concrete way of thinking, savant characteristics, non-compliance, aggressive behavior, sleep disorders, and eating or feeding problems<sup>30</sup>. Unfortunately, there is no space here to explain these symptoms in more detail. Important at this point is to keep in mind how far-reaching autism is.

## 3.3 Growing Up

Since autism is a pervasive developmental disorder and there is no cure, the disorder will accompany the individual for a lifetime. As an autistic individual grows older, though, some characteristics will decline, while others will show. In general, the individual learns to compensate certain deficits<sup>31</sup>. In every autobiography written by an autistic adult, the reader can find examples of compensation. Dominique Dumortier learned to understand social codes, although she still has to analyse every way of conduct. She emphasises that it has not become an automatic process, and still requires her full attention.<sup>32</sup> Temple Grandin had to learn to distrust people<sup>33</sup>.

From personal stories it becomes clear that it takes up a lot of energy to lead a normal life when autistic. Temple Grandin says to feel like “an anthropologist on Mars”<sup>34</sup>. Gunilla Gerland became depressed, and a drug addict, because of her being different<sup>35</sup>. Still, it does not have to mean that an autistic individual cannot lead a successful life. Temple Grandin holds a doctorate in animal studies and travels around the world to give lectures on

---

<sup>28</sup> De Clercq (2005), p. 35.

<sup>29</sup> Gerland (2005), pp. 13-14.

<sup>30</sup> For more information and a more complete overview, see: Whitman (2004), pp. 50-92; De Clercq (2005); Frith (1989), pp. 51-174. More information about savant characteristics and the savant syndrome, see: Hermelin (2001); Sacks (1999b).

<sup>31</sup> Frith (1989), pp. 14-15.

<sup>32</sup> Dumortier (2002), p. 95.

<sup>33</sup> Sacks (1999a), p. 401.

<sup>34</sup> Sacks (1999a), p. 408.

<sup>35</sup> Gerland (2005), pp. 165-172.



both animal science and autism<sup>36</sup>. Obviously, the severity of the disorder determines to some extent the life quality of a certain individual. Still, using some sort of therapy can modulate life quality and abilities of autistic people.

### 3.4 Intervention Programs

At present, a number of intervention programs are available to help children with autism. Some of those therapies are very controversial, like holding therapy where a child is held until it does not resist to a human's touch anymore. Others are more widespread, like the TEACCH approach where teaching methods are adjusted to every particular child.<sup>37</sup> Again, there is no space here to explain all of these intervention plans, so there will be a focus on only one type of therapy: ABA.

#### **3.4.1 Applied Behavior Analysis (ABA)**

ABA techniques are derived from classical conditioning principles, operant conditioning principles and cognitive-behavioral studies of learning. In the beginning, one of the major target groups of this intervention program was severely mentally retarded children. Afterwards, it was believed that a more broad type of children could benefit from this kind of therapy.<sup>38</sup> Over time, numerous programs started using ABA techniques, but the most well known program must be the "Lovaas-method"<sup>39</sup>, also called Discrete Trial Training (DTT) or simply ABA<sup>40</sup>. Although there are distinctions between these three methods it would lead us too far to explain those here.

As early as 1962, Dr. O. Ivar Lovaas started to attribute ABA<sup>41</sup>. In 1987 Lovaas<sup>42</sup> published an article that "was able to conclusively prove the effectiveness of receiving highly refined and intensive methods of behavior therapy"<sup>43</sup>. From then on his therapy has been used for children with all kinds of special needs, amongst them autistic children. It is assumed that every type of behavior can be learned, and this is exactly what the purpose of an ABA program is. Children are learned to show certain ways of conduct. They are also cured of certain (bad) habits, by neglecting them. The main advantage of this program is probably that it can easily be transferred to parents, and thus this therapy does not involve professionals or a

---

<sup>36</sup> Sacks (1999a), p. 401.

<sup>37</sup> Information on some intervention plans, see: Whitman (2004), pp. 176-210.

<sup>38</sup> Whitman (2004), p. 178.

<sup>39</sup> More information on the Lovaas-method, see: "The Lovaas Model".

<sup>40</sup> Saffran.

<sup>41</sup> Tian (2001), p. 1.

<sup>42</sup> See Lovaas (1987).

<sup>43</sup> "Pioneers and Practitioners".

professional setting all the time. However, the program has to be applied on a one-to-one basis for 20-40 hours per week in order to be effective.<sup>44</sup> Also, it is assumed that the earlier this kind of intervention program is started, the more effect it has<sup>45</sup>.

#### 3.4.1.1 Main Characteristics

The main characteristics of the DTT teaching strategy are:

1. Skills learned in small steps (very small amount of information at one time).
2. Each step is trained on extensively until mastered.
3. Repetition.
4. Prompting.
5. Positive reinforcement.

Every session consists of an amount of trials that are discrete because they all have a clear beginning, middle and end, all with their own characteristics.<sup>46</sup> Every part will be touched on briefly.

**Beginning:** The beginning, or antecedent, is the instruction given to the student and what has to be done to make the student respond. For instance, a student could be asked to touch a pen and, when he/she does not respond, the trainer could prompt the child. Prompting is helping the child achieving the right way of conduct, in this case, touching the pen.

**Middle:** The middle, or behavior, is how the student responds. There are three possible ways of responding: right, wrong or not. So if our student was asked to touch a pen, the child could touch the pen, touch another object, or not touch anything at all.

**End:** The end, or consequence, is the response of the trainer on the behavior of the student. When the child displayed the right response, the child has to be positively reinforced. Reinforcement can be either telling the child it did a good job, or giving it food or a toy it likes. When the response was false, or when there was no response at all, the trainer should

---

<sup>44</sup> Whitman (2004), p. 180.

<sup>45</sup> Whitman (2004), pp. 282-284.

<sup>46</sup> "What Is a Discrete Trial?"

neglect the child's behavior and start a new trial. Negative reinforcement (punishments) could also be used, but this is usually not encouraged.<sup>47</sup>

**An Example of a Trial:** The trainer and student are sitting in front of each other. On the table between them there are two objects, a pen and a cup. The two objects are on a horizontal line, the pen on the right, and the cup on the left, both at an equal distance of the student. The trainer has done this on purpose, because this is how the first trial was started, and the student has not been observed to truly master this skill (touching the pen) yet. The placement of the pen on the right side is a sort of prompt.

When the trainer caught the attention of the student he begins the trial by saying in a clear voice: "Touch the pen." The student does not respond, so the trainer neglects his behavior and starts another trial. To prompt the child some more, the pen is moved towards the child. The pen is now closer to the child than the cup is.

Again, the trainer orders, in a clear voice: "Touch the pen." This time the student actually touches the pen, so the trainer reinforces the child. In a clear voice he says: "Terrific", and gives the student some time to play with a car. After this, the exercise will be repeated, until the student has fully mastered this skill and does not need to be prompted anymore.

### 3.5 Autistic Families

Autism is a severe disorder that affects the entire life of the individual. This is difficult for the autistic person, but also for the parents and the family. Especially when it was still assumed that autism was caused by a lack of maternal love, the parents were inflicted with a deep feeling of guilt. Even though this thought has changed over the years, parents still feel guilty when they find their infant diagnosed with autism. Questions rise, like whether they should have done more in order to 'rescue' their baby, or whether they are bad parents.

This feeling of guilt is more present during the period when parents are just confronted with the diagnosis. In that period, other feelings like anger, denial and grief also exist. After some time, parents start accepting the diagnosis and start to learn more about autism. Depending on what the possibilities are, they might turn to special services or put their child in an intervention program. At this time, the family might have to cope with a financial burden.

---

<sup>47</sup> "What Is a Discrete Trial?"

In general, raising an autistic child is hard, and has an impact on the whole family. Studies show that parents with an autistic child are at greater risk for a variety of problems, like depression or anxiety. They are also said to worry more about the future of their child than parents of normal developing peers do. Also, the relations between the different members of a family are tested, and parents of autistic children sometimes encounter marital problems.<sup>48</sup>

#### **4. Autism in China**

In Chinese, a disabled person is referred to as “incomplete” and “sick” (*canji* 残疾) or as “incomplete” and “useless” (*canfei* 残废), indicating in some way how disability is or can be viewed in society<sup>49</sup>. Some derivations can also be made when examining the terms used for autism. Autism is either referred to as the “loneliness disease” (*guduzheng* 孤独症) or the “close-oneseelf disease” (*zibizheng* 自闭症). To conceal the deficit more literary terms are used as “children of the stars” (*xingxing de haizi* 星星的孩子)<sup>50</sup> and “rain man” (*yu ren* 雨人)<sup>51</sup>. To one extent, this illustrates how autism is viewed in society. To another extent, terms like *guduzheng* and *zibizheng* point out that the knowledge on autism in present day China might be rather superficial.

Indeed, in comparison to information on autism in general, less is written about autism in China, although interest and writings on this topic are also increasing. To the author’s disposal were some works of researchers, either Chinese or foreign, some articles from and about autistic families, and interviews with parents and professionals at Xingxingyu. Thus two out of three types of sources that were used in the previous chapter are also used in this chapter. Still, there is a much smaller amount of information available compared to the West and deduce an overall story is difficult.

However, this chapter attempts to create an insight in the autism situation in China. It should be made clear though, that one of the main sources (interviews) were part of a qualitative study. Therefore, the situation described does not necessarily resemble the overall situation. Rather, this chapter can point out some tendencies that could be found in the whole of China.

---

<sup>48</sup> Whitman (2004), pp. 233-275. Stories from parents are, for instance, Daens (1997); Lauwers (2004); Park (2001).

<sup>49</sup> For information on disability in Chinese society, see: Kohrman (2005); Stratford (2000). On specific groups, see: Kleinman (1995) for epileptics; Kohrman (1999) for cripples.

<sup>50</sup> Which is a Taiwanese term.

<sup>51</sup> Based on the movie with the same name.

In this chapter the order of the previous chapter will be duplicated, with some exceptions. First, the history of autism in China will be addressed, and afterwards a closer look will be taken at the present day situation. In this regard, topics like diagnosis and intervention programs will be discussed. Different to the previous chapter is the presence of the topic ‘society’. In this part, it will be examined how autism functions within society. It will be discussed that there are two different tendencies, which co-exist and influence the existence of an autism culture in China.

Unfortunately, there were no sources of Chinese autistic individuals to the disposal of the author. In the West, the fortunate and unfortunate aspects of being autistic can be studied through autobiographies. At present this is not possible regarding China. Only articles and interviews concerning parents or professionals in the field could be used. An interesting source is excluded in this way, which is a pity and something that has to be kept in mind while reading this chapter.

However, the main purpose of this chapter is not to give a total overview of autism in China, as was stated above. Rather, this chapter in one way offers the reader an insight in how different the autism situation in China is, compared to the West. In another way, this chapter also presents an introduction to up-coming chapters. In this regard, it attempts to offer the reader some basic knowledge to understand the situation concerning education or parent-child relations. The part on society, presented in this chapter, is particularly important since it will be discussed that those different tendencies exist in every layer of society. To understand this phenomenon, however, the history and current situation of autism in China need to be addressed first.

#### 4.1 History

The first report on autism in China was published in 1987, when doctor Tao Guotai 陶国泰 reported on a case discovered in 1982 in the Nanjing Child Mental Health Centre (Nanjing jingshen weisheng yanjiu zhongxin 南京精神卫生研究中心)<sup>52</sup>. At that moment, Tao was one of the few doctors able to diagnose autism. Another doctor, Yang Xiaoling 杨晓玲<sup>53</sup>, was working at the Beijing Number Six Child Hospital (Beijing daxue fushu di liu yiyuan 北京大学附属第六医院). According to Tian Huiping 田惠平, mother of an autistic

---

<sup>52</sup> Tao (1987); McCabe (2005), par. 8.

<sup>53</sup> Yang (1996), p. 18.

son and principal of Xingxingyu, at that time: “There were only three doctors able to make the diagnosis. They [those three doctors] all studied abroad”.

This indicates a number of problems present at that time. Firstly, there was hardly any knowledge on autism. Since there was such a small number of doctors who had some knowledge on autism, the common people were not informed about this particular disorder. It is conceivable that some children were never sent to a doctor at that time. Also, if parents actually took their child to see a doctor, there could be a rather long time between seeing the first doctor and obtaining a proper diagnosis. Doctors who had some knowledge about autism were situated in big cities like Nanjing and Beijing, so parents often had to travel a great distance in order to get their child diagnosed. This can also be observed through the story of Tian Huiping and her son. Tian Huiping came from Chongqing and went from hospital to hospital before her son was diagnosed at the Beijing hospital. Of course, there are also other stories. McCabe describes Little Zhang, who lived in Nanjing and was diagnosed in the Nanjing Child Mental Health Centre by doctor Tao<sup>54</sup>. In addition, because of the lack of knowledge and the almost non-existence of intervention programs, parents did not receive much help in training their child. The parents of Little Zhang received a booklet about autism - translated by doctor Tao - which was the only kind of assistance available to them at that time<sup>55</sup>. Tian Huiping had a doctor telling her there was no way to help the many autistic children in China<sup>56</sup>.

As years passed by, the number of autism cases reported increased. Tao indicates that in 1984 some eight children were diagnosed autistic. In 1996, some 100 cases were reported. This positive evolution does not have to mean more children are actually suffering from autism, but rather that there is more knowledge on autism, increase of economic wealth, less cases of misdiagnosis and better medical interventions.<sup>57</sup>

Together with the increasing amount of reports on autism, there was also an increasing amount of institutions established, offering help in one way or another. Those include the Autism Committee set up by the Nanjing Health Centre in 1988, and the Beijing Union for Parents of Autistic Children, established in 1991<sup>58</sup>.

---

<sup>54</sup> McCabe (2005), par. 8.

<sup>55</sup> McCabe (2005), par. 8.

<sup>56</sup> Yan (1999), p. 29.

<sup>57</sup> Tao (2005), p. 5.

<sup>58</sup> McCabe (2005), par. 8; Yang (1996), p. 18.

## 4.2 Current Situation

The present day situation is better, as more children get diagnosed at an earlier age, more intervention plans are available, and knowledge on autism - both of specialists and outsiders - is increasing. Still, the problems pointed out above are not totally extinct. Below, the current situation will be discussed, examining both positive and negative elements.

### **4.2.1 Some Statistics**

Up until now, there has never been a national study conducted on the prevalence of autism in China. Therefore, there are no official statistics available on the number of autistic children. Every report seems to make up its own numbers, deferring from some 400 000 to 1,8 million sufferers<sup>59</sup>. Clark et al. argue that if it is assumed that 60/10 000 children are autistic, there have to be an estimated 1,2 million autistic children in China<sup>60</sup>. However, there have been some regional studies on the prevalence of autism, which show very different results, noted down by Clark et al. In Changzhou 常州 (Jiangsu) there were 7 children diagnosed autistic in a tested group of 3 978 children. In Anhui, a study showed that 420 out of 3 559 children were autistic.<sup>61</sup> Obviously, additional research is necessary to conduct reliable prevalence data.

The same problem exists regarding gender. According to Tao, it is said that there are 6,5 autistic boys to one autistic girl, and reports from Beijing even show this rate to be 9:1<sup>62</sup>. Tao explains the difference between the data in China, and between China and the West, in the following way. Firstly, surveys are only conducted in cities and rural areas are not taken into account, which could maybe deform the outcome of the research. Secondly, there could be an emphasis on boys in the studies, maybe because they are regarded superior.<sup>63</sup> Whatever the case, again it is obvious that additional research is necessary.

### **4.2.2 Diagnosis**

Differences in data should not have to do with differences in diagnostic features, since there is a national manual with diagnostic features adopted from international manuals. Also, diagnostic instruments are adopted from the West. Below, both manuals and instruments will be discussed. Problems with diagnoses will be touched on.

---

<sup>59</sup> For instance see: Tao (2005), p. 5; Yang (1996), p. 18; Ma (2003), p. 54. It has to be noted though that some of these articles are not based on specific research. Therefore the presented data cannot be taken for granted.

<sup>60</sup> Clark (2005), pp. 286-287.

<sup>61</sup> Clark (2005), p. 287.

<sup>62</sup> Tao (2005), p. 11.

<sup>63</sup> Tao (2005), p. 11.

#### 4.2.2.1 Diagnostic Manuals

From 1995 on, autism is considered a mental disease as it is from then on mentioned in the *Chinese Category of Mental Disease, Second Edition* (CCMD-2). The diagnostic features necessary to diagnose autism are adopted from the DSM-IV, and are thus the same as in some Western countries.<sup>64</sup>

At present, the third edition of the manual mentioned above - the CCMD-3 - published in 2001, is used. Its features to diagnose autism are still adopted from the DSM-IV. As such, autism is considered a pervasive developmental disorder and a spectrum disorder<sup>65</sup>. The features necessary to diagnose infantile autism are also similar (impairment in communication, socialization and behavior<sup>66</sup>), and the onset of the disorder has to appear within the first 36 months of a child's life.

#### 4.2.2.2 Diagnostic Instruments

The instruments used to diagnose autism are also adopted from the West. Diagnostic instruments are translated and adapted to Chinese culture. Still, there is not much research conducted as to how reliable these Chinese versions actually are. Instruments used include a Chinese version of the *Psycho-Educational Profile* (C-PEP) (*Xinli jiaoyu pinggu liangbiao* 心理教育评估量表), the *Child Autism Rating Scale* (CARS) (*Ertongqi guduzheng pingding liangbiao* 儿童期孤独症评定量表) and the *Autism Behavior Checklist* (ABC) (*Guduzheng xingwei pingding liangbiao* 孤独症行为评定量表). According to Clark et al. one of the instruments used most in China is the *Autism Diagnostic Interview-Revised* (ADI-R) (*Guduzheng zhenduan fangtan liangbiao* 孤独症诊断访谈量表), although this instrument does not seem to occur in research literature as often as the aforementioned instruments do.<sup>67</sup> In this thesis it is not necessary to take a closer look at these instruments, but it is important to note the similarities with the West.

#### 4.2.2.3 Problems

Both a manual and diagnostic instruments seem available. Still, diagnosing Chinese

---

<sup>64</sup> Clark (2005), p. 285.

<sup>65</sup> There are six categories listed under Autism Spectrum Disorders in the CCMD-3: Infantile Autism, Asperger's Syndrome, PDD-NOS, Other or yet to be Specified Pervasive Developmental Disorders, Heller Syndrome and 3 Rett. More information, see: Clark (2005), pp. 287-289.

<sup>66</sup> See 3.2.3.1 for more information.

<sup>67</sup> Clark (2005), p. 290. For more information on Chinese diagnostic instruments, see: Tao (2005), pp. 74-82.



autistic children is not without its problems. One of those problems is the number of doctors currently licensed to formally diagnose autism. In China, diagnosing autism according to the CCMD-3 standards can only be done by psychiatrists. Currently, China is short of psychiatrists, since mental health issues became a focus of attention only during the 1980's.<sup>68</sup>

In an interview, Tian Huiping also addressed the shortage of doctors allowed to formally diagnose autism. She estimated that there were currently 30 doctors in China who could provide the aforementioned services<sup>69</sup>. In addition, it is conceivable that those doctors are operating in larger cities. This means that families in more rural areas not only need the money to go to a hospital, but also to travel to larger cities. The shortage of doctors also explains to one extent why parents still have to go from hospital to hospital before getting a proper diagnosis. This was reported by most parents interviewed and was a topic present in most of the parental essays.

The shortage of doctors can also be pointed out to be the reason of some other current problems. Firstly, a 1999 report of Tian points out that 98% of Chinese autistic children are not diagnosed before the age of three, but rather between 3-10 years old<sup>70</sup>. This has to do with the fact that only 5% of the children instantly get the right diagnosis. 95% of the families are travelling from hospital to hospital to get their child diagnosed.<sup>71</sup> A story presented in the Xingxingyu Newsletter can illustrate this. One mother recalls the following:

*“When my child was three, I already noticed something was wrong and so I took him to a lot of different hospitals in Guangzhou. When he was eight years old there was finally a doctor who diagnosed him autistic. After that he [the doctor] said: “You came too late”. ”*<sup>72</sup>

During interviews, other problems with doctors and diagnoses were also reported. The mother of Zhang Dingqi 张丁琪, for instance, recalled her child never being fully diagnosed. At the time of the interview the child was six years old. The mother described going from hospital to hospital until:

*“When we went to the hospital in Zhengzhou, the doctor drew a question mark next to the word autism.”*

She said they stopped chasing a right diagnosis afterwards. Still, she was attending lessons to help parents with an autistic child, since she herself still believed her child was autistic.

---

<sup>68</sup> Clark (2005), p. 287. For more general information on China and mental health, see: Lin (1995).

<sup>69</sup> For more information, see: Appendices, 2.

<sup>70</sup> This is a problem because it is currently assumed that the earlier autism is diagnosed the more chance there is of helpful intervention, see: Whitman (2004), pp. 33-34.

<sup>71</sup> Tian (1999), p. 4.

<sup>72</sup> Tian (1999), p. 4.

Remarkably, she did not learn about autism through a specialist, but rather because of media reports. In her case, she read an article in a local newspaper about autism and how this disorder is caused by a lack of maternal love. In this regard there are two aspects that have to be considered.

Firstly, specialists seem to play a secondary role in informing the parents about autism. According to Tian, 70% of the families learn about autism through the media<sup>73</sup>. This stresses the lack of professional help. Secondly, 15 out of 16 parents interviewed had never heard about the disorder before their child was assumed to be autistic. Therefore, the chance that their first acquaintance with autism was through the media is rather high. If the reports they received were as wrong as that of the mother of Zhang Dingqi, this could have consequences for both the child and its parents. Parents could be inflicted with a deep feeling of guilt, and could think that there is no way in helping their child. As such, the child would not receive necessary training.

### 4.3 Intervention Programs

In a later chapter, some Non-Governmental Organizations (NGO's) that offer early intervention plans will be discussed in greater detail, but for now only different methods of treatment will be addressed. In this regard, two different tendencies have to be noted. On the one hand, traditional Chinese medicine is said to offer some way of treatment, and even cures. On the other hand, therapies used in the West can be observed throughout China. Both tendencies will be addressed separately.

#### **4.3.1 Traditional Chinese Medicine**

In Chinese medicine, every disease is said to be an imbalance of energy. Autism is seen as a yin-disorder, characterised by social isolation, lack of communication, and apathy.<sup>74</sup> To reconnect neural circuits that have been disrupted and disconnect vital areas of the brain, acupuncture is used<sup>75</sup>.

Some interviewed parents had sent their child to a hospital to receive acupuncture treatment in order to cure their autism. One of those parents was the mother of Pan Xiang 潘祥, who retreated her child before the end of the program because it seemed to be of no use. Indeed, there does not seem to be any scientific reports available to show the effectiveness of

---

<sup>73</sup> Tian (1999), p. 4.

<sup>74</sup> Clark (2005), p. 291.

<sup>75</sup> Clark (2005), p. 291.

acupuncture treatment on autism. Still, acupuncture is said to gain popularity among parents of autistic children.<sup>76</sup>

### 4.3.2 Therapies

The intervention plans discussed in this thesis are to some extent all based on ABA techniques. Therefore, the reader could get the impression that the most used therapy in China is ABA. Clark et al. made a review of treatment literature and treatment protocols of psychiatric centres in Beijing and Shanghai and found that ABA is only provided in “rare instances”<sup>77</sup>. They found that therapies mostly seem to consist of sensory integration therapies, or music therapies, play therapies and other types of relaxation therapies.<sup>78</sup>

## 4.4 Growing Up

As explained at the beginning of this chapter, there were no sources of Chinese autistic individuals to the disposal of the author. It is therefore not possible to outline how their life could look like. Also, no data is available on how many autistic Chinese find a job and how many reside at home or get married and have a home of their own. The latter is occurring though, as Wu Liangsheng 吴良生, the head teacher at the youth department of Xingxingyu, estimated that China has the highest percentage of married autistic adults in the world<sup>79</sup>. A study of Kleinman et al. on epileptics in China could offer a broader perspective in this regard. They suggest that it was very important to a family of an epileptic to find a spouse. In this way the burden of taking care of an epileptic would be transferred to the family-in-law.<sup>80</sup> However, Kohrman points out that finding a spouse is difficult for a disabled Chinese and that most individuals try to keep their disability secret for as long as possible<sup>81</sup>. It is conceivable that the same is true regarding autism.

Although there is not much data available, it can be estimated that few organizations offer solutions. In Beijing there is a branch of the NGO Huiling 慧灵 that offers a kind of boarding service to mentally disabled adults. Most of their trainees are mentally retarded but some autistic adults are also involved in the program. Huiling owns a sheltered workshop and

---

<sup>76</sup> Clark (2005), p. 291.

<sup>77</sup> Clark (2005), p. 291.

<sup>78</sup> Clark (2005), p. 291. For an explanation on sensory integration therapies, see: Whitman (2004), pp. 184-190. On music therapies, see: Whitman (2004), p. 199. On play therapies, see: Whitman (2004), pp. 195-197.

<sup>79</sup> He made this remark after a meeting parents had with a psychologist during my research period. During this meeting, parents repeatedly asked questions like whether their child would be able to find a partner and get married.

<sup>80</sup> Kleinman (1995), p. 1326.

<sup>81</sup> Kohrman (1999).

three small living groups in Beijing, where adults stay with a family during the week. The trainees learn to adapt a certain level of independency. Unfortunately, due to a lack of knowledge, the autistic people enrolled are kept to a minimum.<sup>82</sup>

#### 4.5 Autistic Families

This topic will be addressed in more detail while discussing the parent-child relation in chapter 7. For now, it is sufficient to make some basic remarks on families with an autistic child and what their possibilities are within society.

From the above elaboration it can be assumed that parents are left with the greatest burden in raising their autistic child. In addition, the lack of medical help is not making it any easier. Doctors apparently do not provide much help concerning the training of autistic children. In a survey conducted by Lü and Gao, mothers of autistic children were asked about their needs and problems. They found that mothers mostly wanted lower hospital fees and more medical assistance.<sup>83</sup>

Also, parents seem to have no chance seeing a psychologist to relieve their psychological burden. Both Tian Huiping and Wu Liangsheng emphasised that doctors currently do not advise parents to send their children to intervention plans like Xingxingyu's. In addition, parents recalled doctors telling them there was no solution for this kind of children, since there is no cure. This leaves parents feeling depressed and alone<sup>84</sup>. Wu Liangsheng explained that there is no chance for parents to get any psychological help. He said they could talk to friends or the teachers at Xingxingyu, but "going to a psychologist is of no use".

#### 4.6 Autism and Chinese Society

Obviously, there are still a lot of problems and shortcomings when it comes to fitting autistic individuals into Chinese society. From the explanation above, it could be concluded that there is still an ignorance or intolerance existing towards autism in China. However, this would be a one-sided view. Therefore, it will be discussed that there are two tendencies existing in Chinese society today.

---

<sup>82</sup> Personal communication with Rong Qiang 戎强, working at the service department of the Beijing branch of Huiling, on 27-09-2005. More on Huiling, see: [www.huiling.org.cn](http://www.huiling.org.cn); "Family Care Helps Mentally Ill Youngsters" (2002).

<sup>83</sup> Lü (2005), pp. 51-52.

<sup>84</sup> More on the phases parents go through after finding out their child is autistic, see: 7.2.1.

On the one side, there is indeed an ignorance and intolerance, especially on the level of social intervention. On the other side, however, it will be discussed that there is also a sense of tolerance, mostly on a personal level. Although these two tendencies will be discussed as two rather distinct tendencies, throughout this thesis it will become obvious that these two tendencies co-exist in every layer of society and in individuals.

#### 4.6.1 Intolerance

In an interview, Tian Huiping expressed her feelings about society in the following way:

*“You do not have to talk about autism and how it is regarded in society. Ask how disabled people are treated in society. Our society as a whole rejects (jujue 拒绝) disabled people. We do not talk about the individuals, society as a whole rejects disabled people. This attitude exists for a long time already. It is something I do not approve of.”*

Managing a NGO that advocates for autism in China and being a mother of an autistic son has certainly influenced her statement. She concluded with the following:

*“If I would not do this type of work, I would never think about this.”*

Both of her statements could be used to make some basic remarks about society. Firstly, her feeling of autistic individuals being rejected in China could be interpreted in various ways, for instance by looking at legislations.

In 1990, China passed the “Law of the People’s Republic of China on the Protection of Persons with Disabilities” (*Zhonghua renmin gongheguo canjiren baozhang fa* 中华人民共和国残疾人保障法). In this law, disability is defined as follows:

*“A disabled person refers to one who suffers from abnormalities or a loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal. The term “disabled person” refers to those with visual, hearing, speech or physical disabilities, mental retardation, mental disorder, multiple disabilities and/or other disabilities.”<sup>85</sup>*

---

<sup>85</sup> Translation: Qiu (2002), p. 29. “Zhonghua renmin gongheguo canjiren baozhang fa”, art. 2.

This definition poses some problems in the case of autism, since the disorder is not included<sup>86</sup>. In the law, there is no reference to developmental disorders, let alone autism. Nonetheless, it could be suggested that, since there is no reference explicitly excluding autism either, autism is included. Indeed, informants agreed on the fact that autistic individuals and their families are able to tap into some privileges available to ‘disabled families’. For instance, one mother said to have registered for a second child, which can be done by every mother with a disabled child, despite of the one-child policy<sup>87</sup>.

Still, conversations with parents and staff members at Xingxingyu revealed a feeling of insecurity because “autism is not seen as a disability by law”<sup>88</sup>. There is also some truth in this, for instance regarding the options of education for autistic children<sup>89</sup>.

Departing from problems with legislation, it becomes obvious that there are not many provisions in China at present. To one extent this can be observed through the lack of public intervention plans and the problems with schooling. This explains Tian’s feeling of autism being rejected and the existence of intolerance towards autistic individuals and their families.

Still, she and other informants felt that society was positively changing. Stepping aside from legislative problems, Tian Huiping mentioned the following:

*“It does not matter that much if autism is not officially a disability. If people regard autism as a disability, that is a good thing.”*<sup>90</sup>

She argued there was a considerable change in society, considering the 13 years she had already been working at Xingxingyu. On the one hand, she noticed an increasing amount of doctors licensed to diagnose autism. Secondly, she mentioned an increasing amount of media attention towards autism and Xingxingyu. However, every interviewed teacher, and Tian Huiping, currently thought China to be in a phase of ‘starting to know what autism is’. Wu Liangsheng predicted that “China will certainly get at the level of accepting [autism]” but, since China is facing a whole set of other problems as well, he added: “This needs time”.

#### **4.6.2 Tolerance**

Tian’s statement “If I would not do this type of work, I would never think about this”

---

<sup>86</sup> This becomes particularly apparent when studying the evaluation standards published by the China Disabled Person’s federation (CDPF) (Zhongguo canjiren lianhehui 中国残疾人联合会). See: “Canjiren shiyong pingding biao zhun”.

<sup>87</sup> McCabe (2005), par. 6.

<sup>88</sup> Personal communication with Wang Peipei 王培培, worker at the development office of Xingxingyu.

<sup>89</sup> See chapter 5.

<sup>90</sup> She mentioned this during a conversation about the CDPF. More about this federation, see: [www.cdpcf.org.cn](http://www.cdpcf.org.cn); Kohrman (2005), pp. 83-112.

is an important statement as well, and deserves some further elaboration. During interviews it was remarkable how few parents reported on getting negative reactions of their environment. Two out of sixteen parents recalled vicious reactions. The mother of Pan Xiang reported people calling her son “a fool” (*shazi* 傻子), while another mother reported: “They look at me with angry eyes”. However, these were probably just occasional encounters. Even these mothers agreed with the 14 other parents that there was “a feeling of sympathy” (*tongqing* 同情) among the individuals in their environment, being family, colleagues or strangers.<sup>91</sup>

Considering the current lack of services and the feelings of insecurity and intolerance discussed above, it would probably be more logical if parents felt left out of society more than they apparently do. Of course, parents expressed feeling insecure about their children’s future because of the current lack of provisions and help. Still, when they were asked about their immediate environment, there were few reports of feeling neglected or not tolerated.

One explanation of this tendency could be found in a study of Lew on cultural values. He argues that both tolerance and solidarity are values inherent to Chinese culture.<sup>92</sup> Furthermore, Lew also found that every parent knows how important it is to a family to have a successful child<sup>93</sup>. This could both explain why people tolerate and sympathize with autistic families and the exclamation Tian Huiping made while elaborating on this feeling of sympathy:

*“This sympathy is given to the families, not to the children.”*

Maybe this has to be softened down, since parents reported particular family members (especially grandparents) to be fond of their child. Still, the increasing amount of media publications reporting desperate parents who are on a verge of killing their selves but try to hang on for the sake of their child<sup>94</sup>, together with a lack of reports on autistic individuals, could to some extent explain this tendency. There is still a lack of knowledge on autism, and stories in the media give a one-sided view. The environment of an autistic family could sympathize with parents without knowing about the disability and thus not considering the child. Also, this feeling of sympathy could actually originate from a feeling of curiosity. Parents reported people being curious about what autism is, because it mostly was the first time they ever heard about the disorder. Reports on family members actively seeking autism-related news were also made. In addition, it could be argued for that, because of the lack of

---

<sup>91</sup> Although it has to be noted that parents reported to be more at ease at Xingxingyu. Maybe, the response of the parents would be somehow different when interviewed in another type of environment.

<sup>92</sup> Lew (1998), pp. 215-216.

<sup>93</sup> Lew (1998), p. 217.

<sup>94</sup> Examples, see: Lu (2005); Ma (2003); Wu (2000).

knowledge on autism and the non-existence of reports of autistic individuals, people think that these children do not have any sense of what is going on whatsoever. This could maybe also explain why sympathy is mostly given to parents.

### 4.6.3 Conclusion

There is a dual feeling both in society and parents of autistic children considering the tolerance and acceptance of autism. When regarding society, it has been discussed that the intolerance visible through legislations and a lack of social help, is added to the feeling of tolerance created by individuals in the immediate environment of the suffering family. This clearly evokes the dual feeling of parents. On the one side they fear the future of their child, since they know how much they could need the lacking help, for instance when advocating for education. Still, their present situation seems not to be made harsher by the reaction of society. Both society and parents will be studied in scrutiny in following chapters, while always keeping in mind this discrepancy of feelings.

## 5. Providing Education for Autistic Chinese

From conversations with parents it became obvious that they were mainly worrying about three things:

1. Whether their children would be able to go to school. This was most urgent, since the children were all six years or older and thus reached the proper age for schooling in China<sup>95</sup>.
2. Whether their children could lead an independent life and would be able to find a job.
3. Whether their children would be able to marry<sup>96</sup>.

Since the scope of this thesis is set on children, and not adults, with a disorder in the autism spectrum, this part will be about schooling and helping these children to be able to attend school.

In 1986 China proclaimed the “Compulsory Education Law of the People’s Republic of China” (*Zhonghua renmin gongheguo yiwu jiaoyu fa* 中华人民共和国义务教育法), which

---

<sup>95</sup> This was also obvious from the parent-child interaction during the lessons at Xingxingyu, although it has to be repeated that I attended the classes for children who already reached the age of six. Tian Huiping explained that the parents at the “preschool department” (*xueqian bu* 学前部) are much more relaxed since their children are 3-6 years old and thus do not have to go to school yet (preschool is not included in the period of compulsory education in China, McCabe (2003), p. 16).

<sup>96</sup> Although parents worry their grandchildren would be autistic as well.



stated that all children, including the disabled, have the right to attend nine years of school. In the regulations “Suggestions on the Implementation of the Compulsory Education Law” (*Guanyu shishi yiwu jiaoyu fa de ruogan yijian* 关于实施义务教育法的若干意见) of 1986, the following can be read in article 10: “When implementing the Compulsory Education Law, local governments at all levels should attach great importance to compulsory education for the blind, the deaf and the mute, the mentally retarded, and other handicapped children, systematically arranging for them to go to school.”<sup>97</sup>

This implies that autistic children have the right to go to school, which would be good for numerous reasons. Not only would this be a relief for the parents, not having to deal with their child twenty-four hours a day, it would also be good for the children. They would get some education and could improve their social skills.<sup>98</sup> Knowing that autism is a disorder that affects the ability to communicate and socialize, the latter is an important aspect.

In China, disabled children have three options for education. The most common option is “mainstreaming” (*suiban jiudu* 随班就读)<sup>99</sup>, in which children with different abilities follow classes with normal-developing peers. Another option is going to a regular school, but attending a class for children with special needs. The third option is going to a “special school” (*teshu jiaoyu xuexiao* 特殊教育学校) that focuses on one type of disability.<sup>100</sup> In the two following parts both education in special schools and in normal schools will be discussed. Since there is a duality between theory and practice, every part will contain some information about the form of education in general, and what this means for autistic children in particular.

The information used in this chapter will be based both on printed literature and interviews held with teachers and parents. The parental essays were also consulted. This gives an interesting view. On the one hand, these different types of information complement each other. Still, different opinions were also observed. Therefore, for the sake of completeness, it has to be added that two out of sixteen parents interviewed did not plan on sending their child to school. When asked for reasons they answered sending their child to school was not realistic. By this they meant the child had already passed the proper age for schooling and still did not have the proper abilities. Deng et al. also argue that some parents with a disabled child, in rural areas, do not see the point in sending their child to school. The parents not having

---

<sup>97</sup> Translation: Yang (1994), pp. 96-97.

<sup>98</sup> “Li Jinglin fuqin de hua” (1997), p. 36.

<sup>99</sup> Deng et al. argue that there are still some differences between *suiban jiudu* and mainstreaming or inclusive education, but this is beyond the scope of this thesis (Deng (2001), p. 291). Other terms for inclusive education include *yitihua jiaoyu* 一体化教育 and *quannaxing jiaoyu* 全纳性教育 (McCabe (2003), p. 16).

<sup>100</sup> Deng (2001), p. 291.

attended school themselves is pointed out as one of the reasons. Other reasons include stories heard about disabled children earning good money (e.g. blind fortune tellers), and questioning why education is important if a child as theirs can live by the help of the community.<sup>101</sup>

Neither of the parents at Xingxingyu pointed out this kind of reasons. Maybe them not sending their child to school could have to do with the ability of the child. It might seem stupid to send your child to school to learn things when it is not even able to go to the bathroom by itself. Also, stories about autistic children attending school in China are rather rare<sup>102</sup> and stories about children being kicked out of school are numerous<sup>103</sup>. For these reasons parents could easily loose their faith and stop advocating for their children.

Still, most of the parents interviewed were willing to send their child to school. This could have numerous reasons, some directly linked to the examined group. Firstly, organizations like Xingxingyu learn their students skills to attend school, and this is the main reason why parents go to Xingxingyu in the first place. Secondly, as explained by Tian Huiping, children who have a severe disorder in the autism spectrum are mostly kept at home, since their parents do not see the point in training their child. This means the children attending Xingxingyu - and probably also other organizations - have a not so severe disorder and can be trained to attend school. The focus below will be on those parents who were planning on sending their child to school.

## 5.1 Special Schools

### **5.1.1 In Theory**

In China, special education came with European missionaries setting up schools for mainly the blind and the deaf. After the founding of the People's Republic of China, all the schools previously set up or sponsored by foreign organizations became public schools. Still, some foreign influence could be noted as schools were set up after Russian example. After the Cultural Revolution, when there was almost no form of (special) education, new laws and regulations asked for more opportunities for children to attend school.<sup>104</sup> Due to the fact that it was impossible to set up many new special schools, these laws and regulations caused a new trend in educating disabled children, as more children got enrolled in normal education

---

<sup>101</sup> Deng (2001), p. 292.

<sup>102</sup> Although not none-existing, one example is Li Jinglin (Zhen (2000), pp. 16-22), see 5.2.2.

<sup>103</sup> Parents in the Xingxingyu Newsletter and the parental essays write about this. Also during interviews this was a reoccurring topic. For instance see: "Guduzheng jiazhang tan (2)" (1997), pp. 47, 50.

<sup>104</sup> Yang (1994), pp. 94-96.

schools<sup>105</sup>. This does not mean there are no special schools available nowadays. It does mean that the biggest group of disabled children attending school is not educated in special schools.

Special schools are mostly set up for three different groups: blind, deaf and mentally retarded children<sup>106</sup>. Teachers in special education schools are trained to teach their target group. Also, classes are smaller than in regular schools.<sup>107</sup>

### 5.1.2 In Practice

There is not much data available about autistic children attending special schools, but some estimations can be made. Looking at the three main target groups for special education, it is not obvious to place autistic children in one of those groups. If an autistic child goes to a special school it would be to a school for mentally retarded children, but still there are some differences between these two groups<sup>108</sup>. This means that it is not so obvious to send an autistic child to this kind of schools.

For teachers at schools for mentally retarded children, teaching an autistic child is not obvious either. They have not been trained for this kind of children, who often ask for a different way of teaching.<sup>109</sup> Due to the fact that their IQ does not have to be lower than the IQ of normal functioning children, autistic children are able to learn a lot, depending on how severe the disorder is. It just takes them a long time before they learn something new and the teacher has to go through the same material over and over again.

In addition, it has to be noted that autistic children sent to special schools probably have a more severe or visible disorder. It was obvious from interviews that parents wanted their children to attend normal schools. It could be assumed that parents would only send their children to a special school when normal schools would not accept their child. This means that those children who are more or less able to act as a normal student do not end up in special schools, and that the problems of autistic children who do attend special schools are more serious.

Another problem reported during interviews was the lacking of those special education schools. Parents mostly did not know any special schools in their neighbourhood and therefore said it was necessary to get their child into a normal education school.

---

<sup>105</sup> Yang (1994), pp. 94-100; Deng (2001), pp. 289-295. See 5.2.

<sup>106</sup> Yang (1994), p. 101.

<sup>107</sup> Xue.

<sup>108</sup> Sun (1998), p. 34.

<sup>109</sup> Sun (1998), p. 34.

Distance or teachers are not the only problems though. Parents may have a difficult time admitting that their child is autistic and even a harder time making this public<sup>110</sup>. Sending their child to a special school would mean a loss of face<sup>111</sup> and thus children are mostly send to normal schools. In addition, parents want their children to learn things like maths and Chinese language, things they would learn in a normal school, not in a special school<sup>112</sup>. A study by Liu on parental involvement in schools for mentally retarded children in Beijing shows similar results. Their survey showed that parents and teachers had a significant different view of education. Teachers thought it was particularly important to learn the children basic skills necessary in everyday life. Parents wanted their children to gain knowledge.<sup>113</sup>

To conclude, sending an autistic child to a special school is not obvious, neither for child and parents, nor for teachers. Still, some special education schools are known to enrol autistic children nowadays<sup>114</sup>.

## 5.2 Normal Schools

### **5.2.1 In Theory**

Due to the law of 1986, efforts were made to educate disabled students. In some areas implementing the law caused problems, since it was not possible to build new school buildings and hire new educators to set up special schools. As a solution disabled students are being integrated in regular education classes.<sup>115</sup> As such, new buildings or teachers were not necessary. Over the years the number of disabled students being enrolled in regular classes increased.<sup>116</sup>

On the other hand, this movement caused new problems. According to McCabe, schools started to enrol disabled students long before they thought about the problems that could come up, such as teachers not being trained to handle students with special needs<sup>117</sup>. Not only are they not trained to work with disabled students, they are mostly not trained to teach individuals, although disabled students need to get some individual training<sup>118</sup>.

---

<sup>110</sup> Fang (2000), p. 14 among others.

<sup>111</sup> Xue.

<sup>112</sup> “Li Jinglin fuqin de hua” (1997), p. 36.

<sup>113</sup> Liu (2001), p. 15.

<sup>114</sup> Yang (1996), p. 19. One example is the “Haidian Special Education School” (Haidian peizhi zhongxin xuexiao 海淀培智中心学校) in Beijing. For more information, see: <http://happyonline.com.cn>.

<sup>115</sup> McCabe (2003), pp. 16-20; Deng (2001), pp. 291-292.

<sup>116</sup> McCabe (2003), p. 17; Deng (2001), pp. 294-295.

<sup>117</sup> McCabe (2003), p. 19.

<sup>118</sup> “Suiban jiudu jiaoxue jihua de neirong”.

Classrooms in China can have up to 75 students, so teachers are trained to teach large groups. On top of this, the qualification of a teacher is evaluated by the test results of his/her students. Having a disabled student in class that cannot achieve appropriate results can thus become a problem for the teacher.<sup>119</sup> Moreover, education is seen as a kind of service for those who can later on contribute to society. Since children with mental retardation are doubted to be able to learn and thus contribute to society, teachers are sometimes less willing to teach this kind of children.<sup>120</sup>

Another problem is found in the attitudes of parents of normal-developing peers. In a study conducted by Niu et al. the attitudes of parents of both disabled and non-disabled children towards *suiban jiudu* were compared. They found that parents of normal-developing children are rather distrustful towards inclusion, since they fear their children will actually learn less or will not get the deserved attention from the teacher. This attitude was especially found in parents whose children had a mentally retarded child in class.<sup>121</sup>

On top of this, since little adjustment is made to the curriculum, it is sometimes hard for disabled students to follow in class. To help them it happens that they get a partner, being someone of the better students. These students have to help the disabled child with schoolwork both inside and outside of class. Also, disabled children are set lower test pass marks and are given easier homework.<sup>122</sup> If the child's capacities are not sufficient, it has to double its year<sup>123</sup>, although this is not encouraged. When a disabled child completed nine years of education<sup>124</sup>, it does not really seem to matter in which grade it is. The 1994 regulations "Methods of Launching the Work of *Suiban Jiudu* for Children and Youth" (*Guanyu kaizhan canji ertong shaonian suiban jiudu gongzuo de shixing banfa* 关于开展残疾儿童少年随班就读工作的试行办法), also point out that mentally retarded children do not have to go through all the different levels of compulsory education<sup>125</sup>. It seems that the first goal is not to get children educated, but just to implement the Compulsory Education Law by giving this children a seat in a classroom. Some authors also state that integration in regular classrooms makes the disabilities of the children more visible to themselves, since they are confronted with normal peers the whole day. This could lead to the disabled student feeling

---

<sup>119</sup> McCabe (2003), p. 19.

<sup>120</sup> McLoughlin (2005), pp. 278-282.

<sup>121</sup> Niu (2005), p. 73.

<sup>122</sup> Potts (2000), p. 306.

<sup>123</sup> Merry (1998).

<sup>124</sup> Being the nine years concluded in compulsory education.

<sup>125</sup> "Guanyu kaizhan canji ertong shaonian suiban jiudu gongzuo de shixing banfa", art. 34.

inferior.<sup>126</sup> Integration is not all bad though, since disabled children get a chance to live along their normal peers and thus get a chance to integrate in society<sup>127</sup>.

To conclude, although integrating disabled students in regular classrooms is a good way to let children receive education, the implementation is still going through some problems. And although parents might think that their children receive a proper form of education this way, e.g. ‘book wisdom’, being integrated in a regular classroom still can be found problematic for the student itself. Moreover, parents of normal-developing children are not always accepting this form of education when their own children are concerned.

### 5.2.2 In Practice

When asked to what kind of school they would like to send their child to, all the parents interviewed answered they would send their child to a “normal school” (*putong xuexiao* 普通学校). Many parents were surprised when asked why they apparently were not planning on sending their child to a special school. Some parents explained that there were no such schools near the place where they lived, but this is probably not the only reason. Looking at some messages parents posted on the chat forums of the websites of training institutes for children with autism, and looking at some articles published in the Xingxingyu Newsletter, all lead to the same conclusion: parents want to send their child to a normal school. In this regard, it also has to be noted that the educational level of a person is very important in Chinese culture<sup>128</sup>, and that parents think the most important task of a child is to study<sup>129</sup>.

Adding this to the knowledge gained from both the parts on special schools in practice and on normal schools in theory<sup>130</sup> it may be clear that most autistic children in school seem to be attending normal schools. McCabe argues that because of the *suiban jiudu*-movement a small but growing number of autistic children are able to attend school. On the other hand she adds that this seems more to be because parents persist in their efforts to let their child attend school, than because of any school initiatives.<sup>131</sup>

Talking to parents and going through some written personal stories made it obvious that although there is a compulsory education law, sending an autistic child to a normal school is still quite difficult. The first problem seems to be finding a school that accepts the child. A child being denied at a certain school was a frequently heard topic. There seem to be

---

<sup>126</sup> “Ruozhi'er suiban jiudu shi hundu? Zhuanjia jiazhang yijian bu yi”.

<sup>127</sup> Yan.

<sup>128</sup> Ji (1993), pp. 824-825.

<sup>129</sup> Bowes (2004), pp. 55-56.

<sup>130</sup> See 5.1.2 and 5.2.1.

<sup>131</sup> McCabe (2003), p. 20.

numerous reasons, like the reputation of the school or the child not adjusting to the environment<sup>132</sup>. Parents could rely on the Compulsory Education Law and accuse the school, but Tian Huiping exclaimed:

*“They could bring this [their child not being accepted in school] to court, but would they win?”*

It has to be admitted that children benefiting from *suiban jiudu* are mostly children with a visual or a hearing disorder, or children with a mild form of mental retardation<sup>133</sup> and not children with a more severe disorder. For some schools the challenge of educating an autistic child could be too big and the problems could be too hard to overcome. It cannot be denied though that parents are putting a lot of effort in advocating for their child to attend school.

All of the parents interviewed - willing to put their child in school - said they thought of accompanying their child until it was totally accustomed to the environment<sup>134</sup>. Some of those parents also said they would not stop training their child at home and were thinking of letting the child go to school for half a day and training it for the rest of the time. Still it seems that, despite all the efforts made, and the “relations” (*guanxi* 关系) used, the results are not always accordingly.

This does not have to mean that autistic children cannot go to school at all, or that they cannot be successful. The most famous successful case seems to be Li Jinglin 李景琳, whose parents come to speak at one of the parental meetings of Xingxingyu every semester, and whose mother wrote some articles for the Xingxingyu Newsletter.

Zhen Yuelai 甄岳来, mother of Li Jinglin, put a lot of effort in keeping her child in school, which is the problem after the child gets accepted. She trained her child not only in subjects like maths and Chinese language, but also taught her daughter to communicate with other children. Although Li Jinglin initially was not accepted in kindergarten, the mother trained her child in that way that Li Jinglin, successfully, finished both primary school and high school.<sup>135</sup> Although the mother also recalls there was an enormous stress factor involved, both for mother and child<sup>136</sup>, in the eyes of other parents she seems to be a role model.

---

<sup>132</sup> “Guduzheng jiazhang tan (2)” (1997), p. 47.

<sup>133</sup> “Zhongguo suiban jiudu fazhan zhuangkuang”.

<sup>134</sup> Although, as some parents said, not all schools are willing to let parents stay during class.

<sup>135</sup> Zhen (2000), pp. 16-22.

<sup>136</sup> To that extent that they had to withdraw Li Jinglin from school for one year while attending high school, Zhen (2000), p. 22.

It could be because of such stories that parents start to persist more in letting their child attend school, leading to a higher number of enrolments among autistic students. But, although the stories of these mothers have a happy ending, they also tell us something less positive: children have to be trained before they enter school. In other words, schools are maybe becoming more willing to teach autistic children maths, stories about teachers helping autistic children overcome specific difficulties, related to their deficit, are still rare.

The most famous positive story in this regard is probably that of Fang Jing 方静, establisher of a training institute for autistic children in Qingdao, and her son. Fang Jing recalled that through the efforts of some understanding teachers her child overcame most of his problems. There seemed to be a good communication between the school and the parents. Also, the teachers seemed to be willing to learn about autism and to help the boy.<sup>137</sup>

Despite of this story, most of the parents now still have to prepare their children for school in a very thorough way, and have to persist in this while their child is in school. Above of this, they have to protect their child since it is an easy target for bullies<sup>138</sup>. This seems not to refrain too many parents from trying to let their child attend school though.

### 5.3 Conclusion

Although legislations made it possible for autistic children to attend school, in reality there are still some problems to overcome, especially when it comes to autism. Special education schools are not available everywhere and when they are, they mostly lack the expertise to deal with autistic children. Normal education schools are reluctant to enrol them. Currently, advocacy of parents seems to be the driving force in whether or not children receive education. Not only do parents need to search a school willing to enrol their child, they also have to train their child in going to school and helping their child in mastering knowledge and skills acquired at school.

Also, from the above explanation it becomes obvious that schools do not have the duty to learn the children skills as going to the bathroom and sitting through a class. Therefore, it seems necessary to find an organization to train the child before it has reached the proper age for schooling. Some of these organizations will be discussed in the next chapter.

---

<sup>137</sup> Fang (2000), pp. 13-17.

<sup>138</sup> Most parents interviewed expressed their fear in this regard.



## **PART II: CASE STUDY**

### **6. Early Intervention Plans**

It seems obvious that some skills are needed to attend any kind of education. Before children even enter kindergarten, they have to be able to do some things independently, e.g. going to the bathroom or feed themselves. They also have to have some basic knowledge about things to do and not to do while being in class, e.g. sitting down in a proper way. Adopting these skills normally goes natural, but autistic children have huge problems acquiring these skills and this does not go natural at all, it has to be taught. This special group of children thus has to go through some kind of intervention even before attending kindergarten.

It could be assumed that parents are responsible for this kind of training. This is partly true, but also supposes that parents need to know how to handle their autistic child and need to have the right strategies for training. In most cases, they need somebody to guide them in handling their child. Parents with the same problem helping each other on a personal level could be an option, but interviews showed that most parents did not know any other children with the same kind of disability in their neighbourhood. Some parents said they thought some children in their direct environment were autistic, but there never seemed to be a lot of interaction between families. Thus, other solutions have to be found.

The first part of this chapter will therefore deal with intervention plans. According to McCabe, early childhood intervention programs have been set up by both government-funded public organizations and NGO's<sup>139</sup>. Since information on both types is hard to collect and since my main source, being Xingxingyu, is a NGO, the organizations discussed in this chapter will all be private organizations. Moreover, they are all linked to Xingxingyu since they are all enrolled in a training service network organised by this institute<sup>140</sup>. Since few printed literature about this kind of NGO's is available, the elaboration is based on analysing their official websites<sup>141</sup>. Giving a complete overview of all the available options is not the goal of this thesis, therefore these organizations give a representation about some early childhood intervention programs in China, without ever stating that there are no other kinds of programs available. Still, by examining some of these organizations, some basic tendencies can be observed.

---

<sup>139</sup> McCabe (2003), p. 20.

<sup>140</sup> The researcher received a list from Xingxingyu with the 33 organizations enrolled in the network in the summer of 2005, see: Appendices, 3.

<sup>141</sup> For their official websites, see: Appendices, 3.

Afterwards, Xingxingyu will be discussed in detail as a case study, since this organization has a prominent position in the autism culture in China today. Not only do most parents of autistic children seem to know Xingxingyu and Tian Huiping<sup>142</sup>, apparently Xingxingyu is taken as an example for other institutions as well.

## 6.1 Non-Governmental Training Institutes

In a study, Wei compared NGO's working with autism in China. It was reported that these organizations did not have a comfortable position in society. Governmental assistance is almost non-existent, which leaves the organizations with numerous burdens. Not only are there the financial problems, there is also a lack of expertise and too many different target groups that have to be addressed. Organizations have to support both parents and children and need proper techniques for doing this. Wei particularly reported a lack of expertise when it comes to teaching autistic children.<sup>143</sup>

Indeed, when examining some NGO's these problems are noticeable. Every organization examined seems to focus on children, but almost every organization wants to involve parents as well. Some organizations only offer the parents a secondary role in teaching their child (observing), others need the parents to actively participate. Still others say to offer some form of psychological assistance offered by specialists. Apart from problems with target groups, financial problems can also be observed. Some organizations mention their financial problems on their websites, but moreover the problems are noticeable because of the fees that are charged. Fees from 700-1000 *yuan* per month seem usual.

Below, no attention will be given to these problems, although they have to be kept in mind. What will be pointed out are some major tendencies, despite of the problems encountered.

### **6.1.1 Major Tendencies**

All the organizations examined are rather new. The earliest organizations<sup>144</sup> were established in 1994, when they mostly did not serve autistic children. The Guangzhoushi Baiyunqu xiaotaiyang teshu ertong kangfu zhongxin 广州市白云区小太阳特殊儿童康复中心, for instance, was established in 1994 but served only deaf children at that time. Their intervention program for autistic children has not been set up until 2003. It seems that, with

---

<sup>142</sup> For instance see chat forums like the one on [www.elimautism.org](http://www.elimautism.org).

<sup>143</sup> Wei (2004), pp. 63-65.

<sup>144</sup> Apart from Xingxingyu, which will be discussed in detail below.

some exceptions, early childhood intervention programs, privately run, are set up from 2000 on.<sup>145</sup>

Most programs have been set up by parents with an autistic child. On top, most of these parents seem to have attended Xingxingyu to help their own child before setting up their own organization. The programs that were not set up by parents of autistic children are usually not solely dealing with autism.

Some organizations, like the above mentioned organization in Guangzhou or the Humiao ertong fazhan zhongxin 护苗儿童发展中心 in Guangdong, serve a whole range of children with various disabilities, from children with language and learning disabilities over children with Attention Deficit Hyperactivity Disorder (ADHD), to children with autism. Most of these organizations seem to have different classes where different learning strategies are used, according to the children's needs.

The early intervention programs for autistic children of the organizations that serve a whole range of children are similar to the organizations that only serve autistic children. Firstly, these programs all use ABA<sup>146</sup>, although mostly mixed with other types of therapies, like sensory integration therapy. Secondly, the age range for the children being accepted is mostly between 2-7 years old, and for most of the programs the parents have to accompany their children. How many children an organization can take up at once varies. Some are just small classes, others take up to 100 students at one time, like the Qingdaoshi Shibeiqu zibizheng yanjiuhui 青岛市市北区自闭症研究会.

Mostly no requirements are made regarding the children entering the program, except for the already mentioned organization in Guangzhou. They have a boarding school that only accepts children with some basic language skills, who do not have any behavioral problems and can do some things independently.

Other organizations work with a boarding school-system as well, where children (and their parents) live in the neighbourhood in rented rooms. Some organizations also work on a day-by-day basis, where children are brought in the morning and go home after class.

All programs seem to be long-term programs, where parents can decide when they withdraw their child. Although most of the organizations argue that the children should at least go through three months of training. One of those organizations is the already mentioned organization in Qingdao.

---

<sup>145</sup> For more information, see: Appendices, 3.

<sup>146</sup> But this could also be because they are linked to Xingxingyu, that attributes ABA skills for years, see 6.2.1.

## 6.2 Case Study: Beijing Xingxingyu jiaoyu yanjiusuo 北京星星雨教育研究所

As already stated, all the above mentioned organizations are linked to Xingxingyu<sup>147</sup>. Xingxingyu says to be the first NGO set up in China to help autistic children and their parents. Since they exist for 13 years now, and thus have more experience than the above mentioned organizations, it is worth examining this organization in detail. The sources used include observations, interviews with principal, teachers and parents, Xingxingyu's official website and some printed literature, like the Xingxingyu Newsletter.

### 6.2.1 History and Current Situation

Xingxingyu was established by Tian Huiping, mother of an autistic son, in 1993. At that time she went from hospital to hospital to find a solution for her son, diagnosed autistic in 1989. When she found out there were so many families who had to go through the same as she had, and that doctors did not provide a lot of help, the idea began to rise to start a program to teach autistic children.<sup>148</sup>

Tian quit her teaching job at a university in Chongqing and started an independent class for autistic children in a private preschool in Beijing<sup>149</sup>. At that time the class had six students and six teachers<sup>150</sup>. Due to financial problems, Tian was not able to pay her teachers' wages, and within three months, two teachers left<sup>151</sup>. On top of that, since the class had not made the amount of money the private preschool had hoped for, Xingxingyu was forced to move<sup>152</sup>.

In June 1993 they moved to an old classroom of the Haidian Special Education School<sup>153</sup>. At that time there were already eight children in the program but still there was no real teaching strategy. According to the website of Xingxingyu, at that time they were "working and learning at the same time" (*bian gongzuo bian xuexi* 边工作边学习).<sup>154</sup>

In September 1993, Xingxingyu moved for the second time, now to the "China Rehabilitation Center for Deaf Children" (Zhongguo long'er kangfu zhongxin 中国聋儿康复中心), where it remained until October 1995. On the previous locations children and teachers

---

<sup>147</sup> Some organizations not linked to Xingxingyu can be found on: [www.cautism.com/Class/mingxiao](http://www.cautism.com/Class/mingxiao). Although these organizations operate completely independent of Xingxingyu they show great similarities with Xingxingyu and the organizations in their training service network.

<sup>148</sup> Yan (1999), p. 29.

<sup>149</sup> McCabe (2001), par. 6.

<sup>150</sup> "Xingxingyu fazhan shi nian da shiji".

<sup>151</sup> Yan (1999), p. 30.

<sup>152</sup> McCabe (2001), par. 6.

<sup>153</sup> McCabe (2001), par. 6.

<sup>154</sup> "Xingxingyu fazhan shi nian da shiji".

had always boarded at school, but at this location no boarding facilities were available. Because of this, Xingxingyu became a day school, where children were picked up and dropped off each day. The 14 children attending Xingxingyu at that time stayed for different periods of time, depending on how long parents could reside in the capital<sup>155</sup>. At this time they also started to pay more attention to the parents, organising parental meetings and giving homework that had to be done by both parent and child.<sup>156</sup>

In November 1995, after moving for a third time, they started their current parental training model. Knowing that parents could not ask for a leave to come to Beijing and study for too long, and knowing that parents needed skills to help their children while being at home, Xingxingyu esteemed that training parents was the best teaching strategy at that time. Parents had to attend all classes with their children and, under the guidance of the head teacher, they learned to be the teacher of their child. When Xingxingyu first began this new model, some parents withdrew their children because they doubted the new strategy, leaving only four students in Xingxingyu. After a while, though, the word spread in how good the results of the training were, and soon the class had 12 students again.<sup>157</sup>

In 1997, Xingxingyu was able to buy its own place in Dongxu 东旭 in the Chaoyang 朝阳 district in Beijing. They continued to give parental training to a growing number of parents. A preschool department was set up, that served parents from children aged 3-6. The parents learned basic ABA skills to teach their children. Every semester contained 11 weeks of training, and parents who finished the semester could come back after a while to improve their skills. For those parents a “feedback class” (*fankui ban* 反馈班) was set up. There was also a “youth class” (*shaonian ban* 少年班) that served the parents from children aged 6-12. This was a five weeks program based on the fact that these children had already reached the proper age for schooling. Thus parents and children got trained in this regard.<sup>158</sup>

In 1998, an “outreach training workshop” (*yidi peixunban* 异地培训班) was started. A group of parents could invite a teacher to their hometown for 10-20 days. The target group of this workshop were parents who could not enter Xingxingyu due to the long waiting list.<sup>159</sup>

Due to the SARS-epidemic in 2003, the school encountered some problems. One of the volunteers working at Xingxingyu at that time got sick and the school had to close down

---

<sup>155</sup> Parents attending Xingxingyu were and still are from all over China.

<sup>156</sup> McCabe (2001), par. 6; “Xingxingyu fazhan shi nian da shiji”.

<sup>157</sup> McCabe (2001), par. 8.

<sup>158</sup> “Model of Parent-Training Program”.

<sup>159</sup> “Xingxingyu fazhan shi nian da shiji”.

for one semester. This made them lose three months of income or an estimated 270 000 yuan.<sup>160</sup>

After recovering from this, the youth class was stopped in 2004 and a “youth department” (*shaonian bu* 少年部) was established. The program still served children aged 6-12 but was extended to a full semester of 11 weeks. During these 11 weeks parents get trained in ABA but with a focus on more academic skills. This department also has a class where parents previously attending Xingxingyu can improve their skills.

Currently, there are 60-80 families studying in Xingxingyu at one time. They stay at places arranged for them by Xingxingyu and they eat at the cafeteria of Xingxingyu. Parents who want to be enrolled in the program have to wait for one year to one year and a half, as explained by Sun Zhongkai 孙忠凯, who works at the development office.

The development of Xingxingyu, its facilities and its teachers, was made possible through the donations and know-how of international benefactors. On the one hand, Xingxingyu needs donations and most of their equipment has a label on it with an expression of thanks to a particular (international) organization. Also, their website lists all the donations recently received. On the other hand, over the years some international organizations and specialists have offered help to Xingxingyu, its teachers and its parents. Recently, Xingxingyu has even established official ties with a service in America that operates on the same line as Xingxingyu does<sup>161</sup>. In this way, Xingxingyu is able to keep on developing.

### 6.2.2 Classes

Currently there are nine teachers at the preschool department and four at the youth department. Every class normally takes up a maximum of eight students and their parents. Below, the classes at the youth department will be described in detail. Still, the organization of the classes is the same for both departments. For both departments the training course of 11 weeks falls apart in three major parts:

1. **Observation:** Covering the first two weeks of the program. Teachers observe the children and put them in appropriate classes. At this time, an Individual Education Plan (IEP) is set up for every child.
2. **Training:** This is the largest part of the course, being eight weeks. Under the guidance of the teachers, parents work with their children

---

<sup>160</sup> “Xingxingyu chongxin kai xue” (2003), p. 30.

<sup>161</sup> “Stars and Rain, Heartspring Enter Sister Organization Agreement”.

according to their IEP. This part of the semester will be discussed in detail below.

3. **Evaluation:** Children and parents are being evaluated and an Individual Family Program (IFP) is set up for the first six months after leaving Xingxingyu.<sup>162</sup>

For both departments every week consists of going to class from Monday to Friday (8.30 a.m. - 11.30 a.m. and 2.30 p.m. - 4.30 p.m.). From Monday to Thursday parents and teachers are working together, on Friday parents are being tested on the skills acquired that week. On Friday afternoon there is a “parental meeting” (*jiazhanghui* 家长会) where the principal or one of the teachers teaches some basic knowledge about autism or explains the skills parents will work on the next week. In a later stadium the parental meetings consist of the experiences of ‘successful’ parents. During the weekends parents are given an assignment in the form of an essay.<sup>163</sup>

The youth department consists of three classes for students who come to Xingxingyu for the first time, and one class for improving the skills of those parents who attended Xingxingyu before. This “improvement class” (*tigao ban* 提高班) can have more students than the other classes (ten in the summer of 2005) and is for only seven weeks per semester. Their program has great similarities with the other classes. There is no restriction in how many times parents can return<sup>164</sup>, but after leaving Xingxingyu for the first time they have to wait for at least half a year before entering the improvement class. Mostly, they have to wait for a year due to a long waiting list.

In the other three classes, children are categorised based on language skills and basic abilities. The class of Deng Xiaoling 邓小玲 consisted of children who all had some basic language skills and had a less visible disorder. The class of Liu Wei 刘伟, the class observed, consisted of children who could utter some sounds, but most of them were not able to express themselves. The abilities of the children varied, and some of them had more visible behavioral problems. The class of Xie Yuqin 谢玉琴 consisted of children without any language abilities, with more behavioral problems and poor basic skills.

These three classes follow the same program. Every morning at 8.30, the children do their morning exercises (*zuocao* 做操) together with their parents and under the guidance of

---

<sup>162</sup> “The 11-Week ABA Training Course”.

<sup>163</sup> “Semester teaching Schedule”.

<sup>164</sup> Dong Nan 董楠 and her mother were already attending Xingxingyu for the fourth time in the summer of 2005.

two teachers. The improvement class participates as well. The exercises take half an hour and afterwards there is either music class or playing a game.

During the music class children have the opportunity to express themselves, as Liu Wei said. This class, again, is under guidance of two teachers who demonstrate the moves to parents and children. New songs are added frequently.

During games, the focus was clearly set on parents and children working together (e.g. moving forward with one foot of both parent and child bound together). At the same time the teachers teach parents some new skills.

At 9.30 a.m., children and parents return to their classes and lessons start. Every lesson, except for snack times, is 45 minutes. The first lesson for my class was always a “demonstration class” (*shifan ke* 示范课). In this class the teacher practices on a one-to-one basis with the child (according to the IEP of the child) and parents watch. Every child gets 15 minutes, so three children are dealt with per demonstration class. After every child the teacher explains some specific difficulties, and gives some further advice to its parents.

At 10.15 a.m. there is a “snack time” (*dianxin ke* 点心课) of 30 minutes, in which children get a chance to practice their communication skills. They are given a biscuit and have to respond in a proper way by saying “thank you”. This class is not given by the teacher but usually by one of the parents. As Liu Wei said:

*“The parents have to learn to deal with different children. The children have to learn to deal with different people.”*

At 10.45 a.m., a “theory” (*lilun* 理论) class starts, in which a whole different range of topics are being discussed. Some of the topics were: different kinds of ABA skills, how to learn your child to knock on the door before entering a room, how to learn your child to eat with chopsticks,... Some of the theory lessons are followed by an exercise.

From 11.30 a.m. to 2.30 p.m. there is a rather long break. Afterwards, classes started again with “arts class” (*jingxi ke* 精细课). Here parents and children work together to make a drawing, a puzzle or another assignment given by the teacher. If children had drawn something, the drawings were always shown at the end of the class. The teacher asked whose drawing it was and the class had to applaud the specific child.

After “fruit class” (*shuiguo ke* 水果课), from 3.15 p.m. to 3.45 p.m., which totally had the same structure as snack time, parents had to perform their skills, first with their own child, later on with other children. This “parent’s operation class” (*jiazhang caozuo* 家长操作) had the same structure as the demonstration class, but the teacher did not intervene while parents



were practising. One parent practiced with one child at the time while other parents observed. After each parent other parents and the teacher gave remarks. Classes ended at 4.30 p.m.

This was the structure of the classes from Monday to Thursday. On Friday, school began with a written examination with theoretical questions on the skills practiced that week. This was followed by a practical examination where parents had to show their skills by training one of the children on a one-to-one basis. In the afternoon children stayed with volunteers in the classes, while parents attended the parental meetings as described above.

### 6.2.3 Teachers

Since there is no special kind of education in China to learn how to deal with autistic children, the teachers working at Xingxingyu learned their skills at Xingxingyu. Some of the teachers like Wang Xiuqing 王秀卿 and Bo Hongli 薄宏莉 are working in Xingxingyu from the beginning and learned by doing. Other teachers, like Liu Wei en Xie Yuqin, studied “social work” (*shehui gongzuo* 社会工作) and first had a “training period” (*shixi* 实习) of one year at the school. In this year they learned about autism and ABA. After one year they had one class with the two of them. After almost two years of training, both of them had an own class for the first time in the summer of 2005.

Aside from teaching children and parents, teachers also have the task to provide psychological assistance. The general view was that it was parents who made the job difficult, not children. This was mostly because their attitudes were hard to change, as said by the principal and all the teachers interviewed<sup>165</sup>.

### 6.2.4 Parents

As stated above, parents attending Xingxingyu come from all across China. Mostly, only one parent, the mother, is accompanying the child. From the eight students observed, seven were accompanied by their mother, one boy had both his parents with him. There are various reasons why not every child is accompanied by both parents. The mother of Zhang Dingqi explained that her husband was not really willing to train his child. A more common heard reason was that the husband was working. The mothers attending Xingxingyu had mostly taken a leave from their job. There were only a few mothers who said they actually quit their jobs because of the child. The reason why most mothers still work seems to be an economical one.

---

<sup>165</sup> See 7.1.3 for more information.

Apart from parents, there were also some grandparents and home teachers attending Xingxingyu. Wang Peipei pointed out that home teachers attending Xingxingyu was a trend that had only come up a few years ago (personal communication). The teachers were not really in favour of this, because, as Xie Yuqin said: “If this teacher goes after a few years, what happens then?” In the newsletter teachers keep explaining that it is mostly the mother who will be with the child for a long time, and thus needs to know how to train her child<sup>166</sup>. Still, the mother of Pan Xiang argued that she needed a home teacher since her child “does not seem to listen” to her.

How parents find out there is such a place as Xingxingyu varies, but no parents said they learned about Xingxingyu through the advice of a doctor. Wu Liangsheng also said that doctors usually do not tell parents to send their child. He said people mostly learn about Xingxingyu through media attention, the internet or parents spreading the word.

The attitudes of the parents towards their child and what they learn varies as well. Wang Xiuqing explained in an article in the Xingxingyu Newsletter that parents who just arrived at Xingxingyu mostly had the same problems:

1. They assume that it is the child that will be trained, not the parents.
2. They are not planning to put in all their effort. They just want to find out if they like Xingxingyu’s strategy.
3. They assume their children will be cured when leaving Xingxingyu.<sup>167</sup>

The third problem is the major problem since parents cannot cope with the idea that their child will never be normal and act accordingly. Tian Huiping said that, from August 2005 on, she very clearly states parents “do not have to expect to have a normal child after Xingxingyu” at the first parental meeting. She said there was no other teacher who dared to give this lecture since “you can see the desperation on the parents’ faces”.<sup>168</sup>

Parents said they felt quite at ease at Xingxingyu. For most of them it was the first time meeting other parents with the same kind of child, so they felt bonded. Parents also helped each other, looking out for each other’s children. On the question if they would still keep in contact after Xingxingyu, all the parents responded they would, and that they would keep in contact with the teachers. The teachers, however, doubted this. They apparently do not hear from most of the parents anymore after Xingxingyu. The teachers all said that this is because “the parents have many things going on after returning home” (Wu Liangsheng).

---

<sup>166</sup> “Gao jiazhang” (1996), p. 17 is just one example.

<sup>167</sup> Wang (1998), p. 9.

<sup>168</sup> See chapter 7 for more information.

Another reason could be that parents stop training their child. As Wu Liangsheng said: “I think only 40% of the parents keep on training their child.”

### **6.2.5 Children**

Xingxingyu only serves children with autism and most of the children are diagnosed as such. Some are not fully diagnosed by a doctor, as said by some parents, but they still come to Xingxingyu. When asked if those children were than diagnosed by the teachers, Wu Liangsheng answered:

*“We do not diagnose children, but parents sometimes seem to make the diagnosis while filling in the forms necessary to enter Xingxingyu.”*

The children in the youth department should be aged 6-12, but in the class observed one boy was five years old. Liu Wei said that his mother had filled out the wrong birthday. She added that this was “not a big problem” (personal communication).

The background of the children varies. Some had gone through a treatment with acupuncture, others had never received any form of training before. Some children had been diagnosed rather late, others had not go through any training because parents thought “it would get better”. In the class observed there was a difference between the abilities of the children, but since every child has its own IEP, the problem did not seem to be that big. Liu Wei said that it did make her job harder (personal communication).

What these children do have in common is that they were all rather old to receive training, since the best period to train children is between 3-6 years old. The reasons for this are a late diagnosis and the long waiting list to enter Xingxingyu. Also, they all reached the proper age for schooling. Some children had already been in a kindergarten for some time, but most of them had been kicked out.

## **7. The Chinese Autistic Family: Focus on the Parent-Child Relation**

Having elaborated on Xingxingyu clearly demonstrates that there are three main actors involved in the institute: teacher, parent and child. These three actors interact with each other and influence each other in many ways. In this chapter the main focus will be the parent-child relation, without omitting the interaction and influence from teacher on parent.

The main purpose of this study is to get a view on how Chinese parents cope with their autistic child, but since it is not possible to pick families with an autistic child at random, the families of Xingxingyu were chosen as participants. Except for the fact that they are all parents to a child with a disorder in the autism spectrum, these parents have some other things

in common. Firstly, parents attending Xingxingyu were all willing to train their child. Secondly, their economic situation allowed them to attend Xingxingyu. Thirdly, the children attending Xingxingyu could have the ability to attend school in the future, partly because they received training, partly because they did not have a severe disorder<sup>169</sup>. Fourthly, parents at Xingxingyu not only receive training in order to teach their child, but some attention is also given to the parent-child relation. Teachers are particularly concerned with how parents view their children and how they cope with them. Fifthly, children at the observed department all were between 6-12 years old, and thus had all reached the proper age for schooling. This can be seen as an extra form of pressure towards the parents.

Despite these points, all families had their personal differences, but still, the fact that they attended Xingxingyu could make them a special subgroup within the group of ‘autistic families in China’. That is why it has to be noted that this is a qualitative study and that no attempt was made to make this study resemble the situation of every ‘autistic family’ in China.

The information for this study was mainly derived from in-depth interviews with principal, parents, and teachers of Xingxingyu. Since parents had already attended four weeks of classes before this research started, it was necessary to question principal and teachers on how parents evolve during their stay at Xingxingyu, from their arrival onwards. In this way the researcher could get a more complete image of the situation of those particular families. Principal and teachers also talked about what happens to the families after leaving Xingxingyu, but since no real research was conducted by Xingxingyu - or researchers - on this matter, those are estimations. In addition to the interviews, corrected parental essays<sup>170</sup> and letters from parents and teachers in the Xingxingyu Newsletter were also used. On top of this, five of the parents interviewed were studied more closely. These parents all attended the class for children with mediate abilities, and the researcher observed this group while participating and helping both teacher and parents during class. All this material will be used below in an attempt to create an image of how some Chinese families react to an autistic child.

Before this material can be used, it is necessary to introduce some elements to create a background for a better understanding on why these families act as they do. Some of these elements were already mentioned in an earlier part of this thesis and will only be repeated

---

<sup>169</sup> See the introduction to chapter 5.

<sup>170</sup> Teachers often wrote some comment in reaction on the parental writings. The main focus here, again, was the parent-child relation.

shortly for the sake of completeness. Other elements are new and request some explanation. Next, the parent-child relation will be examined under closer scrutiny. Two examples will be used to clarify the theoretical explanation.

## 7.1 Background

### **7.1.1 Society**

The reaction of society towards disabled people has already been discussed in part 4.6, so there is no need to repeat it here. It has to be added though, that the way society acts can affect parents in two ways. On the one hand it is conceivable that parents regard disability in the same way as society does<sup>171</sup>, and that it takes some effort to accept the fact that they are raising a disabled child. During interviews the words “loss of face” (*diu mianzi* 丢面子) came up more than once. When asked about the reaction of the environment on her boy, the mother of Pan Xiang answered:

*“We do not go out much, his father drives the car of the head of the community (lingdaoren 领导人) so it is not possible [to take the boy outside].”*

Although, in this example, the words ‘loss of face’ are not used, it is clear that this is what is meant. The father is seen as somebody with prestige and the boy’s behavior could affect the father’s status. For the parents of Pan Xiang the disability of their child makes them leave their child at home. Teacher Xie Yuqin also found it conceivable that some autistic children “are kept inside and are never allowed to go out”.

On the other hand, parents can also be situated on the personal level discussed in part 4.6.2. The mother of Xiaole 小乐, for instance, writes in the Xingxingyu Newsletter that she had always felt very sorry for parents with a disabled child, but that she had never imagined herself raising one.<sup>172</sup> This evokes parents feeling sorry for themselves, which can also be illustrated by the example of the mother of Xiaole. She writes:

*“Actually, it are not the children who feel most alone and helpless, it are the parents.”<sup>173</sup>*

### **7.1.2 Thoughts About Parenting**

At present, Chinese families usually consist of four grandparents, two parents and one child. The child is believed to be the centre of attention, the sun around which everything

---

<sup>171</sup> See 4.6.1.

<sup>172</sup> “Cong dianying ‘canghai chizi xin’ tanqi” (1998), p. 23.

<sup>173</sup> “Cong dianying ‘canghai chizi xin’ tanqi” (1998), p. 23.

revolves, the little emperor.<sup>174</sup> Parents, and grandparents, are willing to do basically everything to improve the child's youth. But other than in Western thought might be, a good youth does not seem to imply giving the child time to play or have fun<sup>175</sup>. It means that the child has to learn. As Lew pointed out in his study about Chinese views on parenting, Chinese families are achievement-oriented<sup>176</sup>. Children will be appreciated according to their achievements. Most of these achievements are academically and, in fact, parents think the most important task of a child is to be good at school<sup>177</sup>. If the child does not live up to the expectations it will be punished, sometimes physically.<sup>178</sup> School is important because the general thought in China is that better educated people get better jobs and have a higher social status<sup>179</sup>. This also explains why it is so important for parents with an autistic child to still send their children to normal schools<sup>180</sup>.

Another expectation towards Chinese children is that they have to show "filial piety" (*xiao* 孝) towards their parents<sup>181</sup>. One of the ways to show *xiao* is to take care of the parents when they are too old to take care of themselves. Parents at Xingxingyu said they were wondering who was going to take care of them when they grew old, since the child might not even be able to take care of itself.

Since parents already create a lot of these expectations while anticipating the birth of their child, these thoughts affect the parent-autistic child relation. The interviewed parents said they wanted their child to "have a good education" (mother of Zhang Dingqi), "have a good job" (father of Yang Yu 杨钰), "go abroad for study" (mother of Yin Jiajun 殷嘉俊) among other things<sup>182</sup>. The question is whether parents can change their expectations in order to meet the actual abilities of the child.

Since children in the examined group were all six years or older, another remark towards parenting has to be made. Parents tend to be very compliant towards small children. They are allowed to show some sort of bad conduct and are not required to achieve any special results, although they will be praised if they can. When children reach the proper age

---

<sup>174</sup> Ji (1993), p. 822.

<sup>175</sup> Lee (2002), pp. 265-266.

<sup>176</sup> Lew (1998), p. 12.

<sup>177</sup> Bowes (2004), pp. 55-56.

<sup>178</sup> Lew (1998), p. 12.

<sup>179</sup> Ji (1993), pp. 824-825.

<sup>180</sup> See chapter 5.

<sup>181</sup> Bowes (2004), p. 49.

<sup>182</sup> The same answers were reported by parents of normal-developing children in Davin (1991), p. 46.

for schooling, parents tend to change. Children of this age are required to achieve good results and are not allowed to show any inappropriate behavior.<sup>183</sup>

### 7.1.3 Xingxingyu

Principal and teachers at Xingxingyu all shared the opinion that it were the parents who were difficult to work with, not the children. This was mainly because the parents were harder to change. As Tian Huiping explained: “Parents want their children to become normal and it has to happen fast.”

In Xingxingyu, a lot of emphasis is put on controlling the mood of parents. This is the first skill parents get trained in, and it was mostly this skill the observed parents had to be reminded of. Repeatedly, parents were asked to smile to their child while working with it, as it would stimulate the children to carry on studying. But mood control meant more than smiling. The teachers wanted the parents to be sincerely happy about every little new achievement the child made, and to ignore its mistakes. Because the expectations for Chinese children in general are high, it was not easy for the parents at Xingxingyu to be happy with the little achievements their children made. As Liu Wei said:

*“Parents do not understand why they should be happy when their child achieved just a small thing.”*

Because the parents have high hopes, a lot of emphasis in Xingxingyu is also laid on lowering expectations. Especially during parental meetings parents are told repeatedly that they do not have to expect their child to achieve a lot instantly. Parents are told that teaching their children new skills can take months, and that regression can occur. They are informed that their expectations affect the development of their child. In one of the parental meetings the manager of the preschool department, Bo Hongli, gave the parents the example of a father previously attending Xingxingyu. None of the achievements the child made had met the expectations of the father. He had continuously told his child it had to do better, up to the point that the child itself said it had to do better with every move it made.

Because of the high expectations, the parents do not praise their child for the results achieved. This is the third point of emphasis towards the parents of Xingxingyu: they have to praise their child for every little achievement made. Telling the child it is doing well is one way of doing this, another way is reinforcing the child by giving it toys or food it likes.

---

<sup>183</sup> Davin (1991), pp. 49-56.

Observations in class made it clear that the parents found this difficult to conduct, and that praising the child was often forgotten.

To point out the importance of praising, a game is played during one of the parental meetings. Parent A has to go outside while other parents discuss what kind of task they want parent A to do, e.g. shaking the hand of the teacher. When parent A enters the room again he has to find out what the other parents expect from him, but he cannot ask any questions. The other parents can only give hints by responding to what parent A does. If he walks away from the teacher they can tell him it is wrong. If he walks towards the teacher they have to praise him. After achieving the goal set, this one parent had to tell how he felt. Parents said they had felt comfortable while being praised but felt disturbed when people were yelling at them for doing the wrong thing.

Basically, teachers are trying to make parents love their child and to make them notice the child instead of the disability. The fact that there was such a strong emphasis on this must affect the parent-child relation in some way.

There is also a second way in which Xingxingyu affects the parent-child relation. Parents were always observing other children and children were compared. This made the parents of the children with better abilities feel better about their child, while parents of children with lesser abilities were less confident. In one way this could explain why none of the parents of the children with lesser abilities were willing to cooperate in the research conducted, while all the parents of the children with better abilities agreed on being interviewed.

Also, attending Xingxingyu makes parents meet other parents with similar problems, which creates a bond. There is a Chinese saying that states that “misery loves company” (*tongbing xianglian* 同病相怜), and this was clearly felt by the parents. They feel more at ease at Xingxingyu, since they know they are not alone and they have people to talk to who understand their situation, as explained by informants.

#### **7.1.4 Family**

Not only high expectations explain the parents’ need to have a normal child. Although most of the parents interviewed said they received help from - and that the child was loved by - the family<sup>184</sup>, Tian Huiping puts it differently:

---

<sup>184</sup> One parent did not have good relations with the grandparents of the child, another parent said the children in her family were not willing to play with her child, because he was so hard to play with. These are isolated cases though, and even these parents said that most of their relatives were good to them and their child.



*“There is a lot of pressure on the parents from their family to bring back a normal child after attending Xingxingyu.”*

Except for one, all parents interviewed said they were feeling at ease at Xingxingyu, and that they feared going back home. The main reason given was the fear to be alone again, since they had finally met parents with the same experiences and difficulties as they have. Another reason was indeed the fear of more pressure.

The family’s love for the child and the need for that child to be normal coexist. One of the reasons is a lack of knowledge about autism. It was particularly while talking about grandparents, that parents noticed misunderstandings about autism. The father of Wang Yilin 王一霖, for instance, said the child’s grandparents pampered the child but did not understand what kind of disability this child might have.

Teacher Deng Xiaoling said to notice a change in the parents when they reached week eight of the semester. She said parents forgot all about controlling their mood again, and that expectations towards the child got higher again. She thought this had to do with the parents having to go home soon.

The pressure that comes from the family and the fact that parents do not feel like people understand their child’s disability could affect the parent-child relation as well.

## 7.2 Parent-Child Relation

These backgrounds coexist in every parent at Xingxingyu and it influences them, although in different ways. In one way this difference of influence has to do with the fact that, for instance, thoughts about parenting or the reaction of the family might differ. On the other hand, it has to do with the perception parents have of their own child. Also, as Wu Liangsheng said, almost every parent has one year wherein “life is very hard” after the child has been diagnosed. Some parents attending Xingxingyu in the summer of 2005 already learned to accept the fact that their child was autistic, other parents were not that far yet. It might be expected that parents who attended Xingxingyu before had evolved more in this process, but according to Wu Liangsheng there is no difference between the parents in the *tigao ban* and those in other classes.

There seem to be some phases these parents have to go through, and parents act differently on their child depending on which level they are in. This process will be touched on first, before addressing the actual parent-child relation through observed cases.

### 7.2.1 Process

Based on her own experiences, Fang Jing learned that every parent has to go through three steps: (1) awaiting the diagnosis, (2) facing the situation, and (3) accepting the disabled child<sup>185</sup>. Every step will be addressed separately.

#### 7.2.1.1 Step 1: Awaiting the Diagnosis

The first step seems to be observing something is wrong with a child and that help of a professional is needed. This step can take some time<sup>186</sup>. Because autism is known on such a small scale in China, it mostly takes some time between going to a doctor for the first time and getting the actual diagnosis as well.

Before the diagnosis, parents try to find out what is wrong with their child, but they cannot think about it as disabled. Parents stated that their surroundings, including the doctor, said there was nothing wrong with the child, or that it was just a late talker or developed a little slower than other children. In addition, most of the parents stated that their children had been able to do a lot of things when they were very young. For instance, the mother of Pan Xiang recalls:

*“When Pan Xiang was one year old he could talk and sing a lot of songs, he was very clever at that time. But on one year and a half he could do nothing anymore.”*

A lot of other parents during interviews and in parental essays recall similar events. This added to the influence of their environment makes the parents wanting to think their child is going to be really clever, instead of being disabled. Fang Jing thought her child to be an infant prodigy<sup>187</sup>, Zhen Yuelai wanted to learn her child as much as possible<sup>188</sup>. The Chinese language even has a proverb for late talkers, saying that they will grow up to become respectable persons (*guiren yuchi* 贵人语迟). These thoughts make it difficult for parents to go to a doctor. Most of the parents recalled that, when it did not get better, they went to a hospital after all. Stories about teachers telling the parents to send their child to a doctor are also known.

All the parents interviewed, except for the mother of Li Jiachen 李嘉琛 who had studied medicine, had never heard about the word autism before their child was diagnosed as such. Because of this, parents come up with many reasons why their child behaves as it does,

---

<sup>185</sup> Fang (2001), pp. 16-18.

<sup>186</sup> According to Clark et al., this step takes an average 31 months. Clark (2005), p. 289.

<sup>187</sup> Fang (2000), p. 14.

<sup>188</sup> Zhen (2000), p. 16.

but they do not think about autism. Most of the parents said they first assumed their child to be deaf, because it did not listen to the things they said. When a hearing test did not show any problems, they supposed: “it would get better”. Other parents assumed their child just developed a little slower than other children, and the mother of Yin Jiajun thought her child to be depressed.

When the diagnosis is finally made a lot of parents have difficulties believing it. Sometimes it is even harder to believe because the doctors are not really sure whether the child is autistic or not. In this case parents seem to continue their search for a more positive answer. The mother of Zhang Dingqi recalls:

*“When the doctor drew a question mark next to the word autism we thought that it would not be autism. It better not be autism.”*

The influence of the environment together with the lack of knowledge on autism makes it difficult for parents to think of their child as being disabled in general, and as being autistic in particular. When the diagnosis has finally been made it means that parents have to change their thoughts both about their child and about disabilities.

During conversations it became clear that parents had many dreams concerning the future of their child. Most of those dreams were made while awaiting the birth of their child, and contained thoughts about the children’s schooling and career. When it is made clear to the parents that their child is autistic and that, at present, no cure exists, parents have to change those thoughts. Although the observed parents truly attempted to change, it was undeniable that they also tried to change their child’s behavior in order to make it act normal.

On top of this, they also have to change the way they think about disabled people in general. Because of the sympathy that exists on the person-to-person level in society<sup>189</sup> these parents also feel sorry for other parents who are known to have a disabled child but, as parents expressed, it was difficult to imagine having a disabled - or an autistic - child themselves.<sup>190</sup> So, shifting from the pity they feel towards other parents to feeling strong enough to handle their own child takes time.

#### 7.2.1.2 Step 2: Facing the Facts

The next step seems to be getting to know the diagnosis and trying to live with it. Wu Liangsheng said parents usually need one year to adapt to the notion of their child being autistic. He could also think about some parents needing three years to adapt to the

---

<sup>189</sup> See 4.6.2.

<sup>190</sup> “Zai Xingxingyu wo xuedao le ai” (2002), p. 24.

circumstances, and on the forum of the website of Qingdaoshi Shibeiqu zibizheng yanjiuhui one mother writes about needing a period of ten years.

Parents stated the diagnosis of their child brought changes to the family. Firstly, parents start to doubt their own skills. The mother of Li Jinglin, for instance, thought she had pushed her daughter too hard in learning too many things and therefore caused her daughter's disease<sup>191</sup>. Other parents thought they had worked too hard and maybe had not spent enough time with their child. The mother of Zhang Dingqi thought she had been too indifferent towards her daughter. The fact that their environment often does not seem to understand something is wrong can make things even worse.

This feeling of guilt makes parents feel depressed, although they usually do not call for professional help. Wu Liangsheng could recall two mothers who had told him they felt depressed during the eight years he taught at Xingxingyu.

Parents also feel desperate because they do not know how to help their child. Doctors do not seem to offer a lot of help, saying there is no solution for this kind of children. The mother of Pan Xiang recalled buying a book about how to teach a child, but it was of no use.

Because of these feelings and the lack of information and knowledge on autism, parents have a hard time training their child. In the essay that parents have to write about their own temper, some parents recalled getting angry with their child very often. In that case they would yell or even beat their child. This resulted in the child not wanting to study anymore and the parents getting more upset.

This mixture of feelings makes parents feel hopeless, up to the point they think of killing themselves and their child<sup>192</sup>. Why parents turn around and start to face the facts, and train their child, can have various reasons, but one of those reasons surely is knowing there are ways to help this kind of children, and that there are places where help is offered. Knowing help is available can be a first step in starting to really accept the child being autistic, but it is not the only step needed.

### 7.2.1.3 Step 3: Accepting the Child

Tian Huiping and all the teachers interviewed agreed that most parents starting a semester at Xingxingyu were not fully accepting their child yet. They still wanted their child to become normal, and to be cured after Xingxingyu. Although efforts are made by principal and teachers to change these thoughts, results seemed not always to be accordingly.

---

<sup>191</sup> Zhen (2000), p. 16.

<sup>192</sup> For instance: Yan (1999), p. 29; McCabe (2005), par. 9.

The fact that so many efforts are made to turn the parents around must have some effect though. This effect was mostly seen when parents were teaching other parents' children during parent's operation classes and tests. All of a sudden the parents were very understanding towards their pupils, and smiled at them constantly. But, when they had to train their own child again, they continued to push the child, wanting it to do things that seemed impossible at that time.

The expectations made on the children remained high. During interviews, parents said that they still had the same dreams and hopes towards their children as they had had before. This means they still hope their children can attend a good school and have a good job. Although parents know their children's abilities are limited, they do not seem to be able to change their way of thinking. This means children at Xingxingyu had to do their utmost, and the pass mark was set by the parents.

Although teachers kept on repeating that mood control and praising the child is important, it was obvious from the lessons observed that it was hard on the parents to be happy about results they found not worthy. Liu Wei said:

*“Parents do not understand why they should be happy when their child achieved just a small thing.”*

And when she thought about her own function she added:

*“Teachers are sometimes happier about the achievements children make than their parents are.”*

Teachers also know they can keep the parents motivated by making the children improve. Xie Yuqin elaborated further on this thought:

*“When children improve, parents are happy. When parents are happy they can train their children better, thus children will improve more.”*

Since changing the parents' behavior is difficult, it is likely that parents are better trainers when they are under supervision (e.g. at Xingxingyu) than when they are back home. Tian Huiping said the environment of the parents wants them to bring a normal child back home, so the pressure is high and three months of training are not going to change that. Teachers also agreed on the fact that not all parents keep on training their child.

It is not obvious to conclude whether a child is accepted by its parents or not and for what reason. The mother of Dong Nan recalled some people telling her to get rid of her child. The fact that she had not got rid of it can be called acceptance towards the child, but this does not have to mean that the child is accepted as an autistic child. Most parents at Xingxingyu all seemed to have high hopes on being able to change their child, to turn it into a normal person.

## 7.2.2 Two Examples

It is not possible to draw solid conclusions on how parents react to their child, since many different factors have to be taken into account. It is possible, however, to look at different cases, and notice the similarities and differences.

Two examples have been chosen for specific reasons. Both families were attending the class observed and both mothers were interviewed. The two stories were quite different and, in my eyes, these stories present the two ends of a spectrum. They formed the greatest contradiction in class. The stories are not given because they present two extremes, but because they can be seen as two distinct stories. It has to be kept in mind that other families behaved in a more moderate way.

### 7.2.2.1 Pan Xiang 潘祥

**Background:** Pan Xiang is a six-year-old boy, who attended Xingxingyu together with his mother and a private tutor. The family comes from Guangzhou and Pan Xiang has an older brother. The original wish of the father was to have a girl, and, since the mother did not want to adopt one, they decided to have a second child. When the second child turned out to be a boy as well, the father was disillusioned and Pan Xiang did not have a name until a doctor urged the parents to give their child one. Pan Xiang was three and a half years old at that time.

Pan Xiang was said to have a normal development up to one and a half years old. From then on all the skills he had learned, like singing songs and reciting poetry, seemed to disappear. When he was two years old his mother took him to a doctor but, after a hearing test, the doctor thought Pan Xiang to be completely normal.

When he was three and a half years old the parents went to the hospital again, although Pan Xiang's grandmother thought the boy only had to be taken out more often. This time Pan Xiang was diagnosed autistic, and the parents started to get really worried. Because a book about training children was of no help, Pan Xiang was brought to a hospital where he stayed for a while. When Pan Xiang reached the age of five he got an acupuncture treatment, but, because the mother was not sure if it was of any use, she retreated the child. At this moment Pan Xiang attended preschool education in a normal school, but after a while he got trained exclusively at home.

**Xingxingyu:** In September 2005 Pan Xiang was attending the class for students with mediate abilities, but before that he had spent some time in the class for students with better

abilities. The mother argued Pan Xiang had switched classes because he and the teacher of his first class did not get along. However, the teacher of the class with better abilities students, Deng Xiaoling, told a different story. She said Pan Xiang did not have the right abilities to be in the higher class and therefore switched classes. Indeed, although Pan Xiang could utter some words, he did not have the same kind of language skills as the children in the better abilities class.

Disagreement between teachers and parent also existed on the progress Pan Xiang made. Although the teacher thought Pan Xiang was moving forward, the mother had a different view. “My child became autistic here” was the mother’s comment when asked about the reaction of the environment on her and her child. She argued that her child had not had any visible problems while being at home, but at Xingxingyu the problems had begun to show<sup>193</sup>. These problems were blamed on the home tutor, on the one hand, and Xingxingyu on the other. The latter can be explained as follows: the children imitated each other’s behavior. The mother of Zhang Dingqi also said that her child had learned to “shout” (*jianjiao* 尖叫) while attending Xingxingyu. This mother seemed not to mind, in contrast with the mother of Pan Xiang, who saw her child ‘becoming’ autistic.

This mother was the only one met in the study conducted who seemed not to be too content with Xingxingyu and the training given. The mother elaborated on the fact that she was not feeling at ease at Xingxingyu, and although she said to have some friends among the other parents of her class, she was awaiting the semester to end.

**Attending Class:** Pan Xiang, his mother and home teacher were the first pupils noticed while observing. Not because the behavioral problems of Pan Xiang were so much more visible than those of other children, but because the way the mother and home teacher dealt with the child. Whenever Pan Xiang made a move, the child was, in an unfriendly way, pulled back upon its chair. Most of the eight children in class could not sit still for a long time, and children often tried to escape. The difference with the other children was the way in which it was made clear to Pan Xiang that he had to rest seated. This sometimes led to Pan Xiang throwing a tantrum.

Some other observations were also made. The mother seemed to lack self-confidence. This became obvious during the interview, when the mother claimed she could not get her

---

<sup>193</sup> Although the mother also said they had not taken their child out while being at home, because this could cause a loss of face to the family. This points out that there had to be some visible problems before the family attended Xingxingyu.

child to cooperate. Also in class, the lack of self-confidence of the mother was obvious. Although repeatedly pushed by the teacher, she never participated during the parent's operation classes. The teacher said there had been one time, during the beginning of the semester, when the mother had trained her child while in class, but afterwards it had always been the home teacher who had done the exercises. During the observation period there had been one time when the teacher had been able to get the mother to do an exercise together with her boy, but after one trial she had gone back to her seat and let the home teacher finish the session.

It was not obvious who trained Pan Xiang outside of class, but it was obvious how the training outside of class went. During one of the parental meetings, Bo Hongli warned parents that they had to praise their child and did not have to criticise every mistake made. Bo said this could have the effect of the child thinking it did everything wrong. Pan Xiang seemed to be one of those children. One of the parent's operation classes went as follows:

Tutor: "Pan Xiang, first clap your hands, than stamp your feet."

Pan Xiang (after making the right movements): "Wrong!"

Tutor: "Very good. Pan Xiang, first clap your hands, than stamp your feet."

Pan Xiang (after making the right movements again): "Wrong!"

...

After this session the home tutor explained that Pan Xiang had been wrong a couple of times while practising at home, and mother and tutor had always told him. The teacher reacted by saying that they had to praise the child more and criticise it less.

**Conclusions:** From this parent and the elaboration above some individual conclusions can be drawn. These conclusions do not give an overall view of the parent-child relation between a Chinese parent and his/her autistic child, but can give some insights into some of the characteristics that Chinese parents might have in their relationship with their autistic child.

Firstly, both the interview and the observations made on this parent show that the disability of the child had not been fully accepted. Not only had the child been sent to the hospital after being diagnosed, to be cured, the mother also claimed her child was not autistic before attending some training for autistic children. For this parent, being surrounded by other autistic children was hard. Not only did the child pick up on some behavior that has been said to give a loss of face, the parent also had to admit the child was having some life long problems.



Secondly, the parent lacked self-confidence and brought this feeling upon her child. It is hard to define the origin of this lack of self-confidence but one of the reasons could be a sense of guilt. In general, parents expressed they felt guilty because their child was autistic<sup>194</sup> and because of the fact they started to train the child too late<sup>195</sup>. Regarding the mother of Pan Xiang there seemed to be some other factors involved. On the one hand, Pan Xiang is a second child and was meant to be a girl. This could bring a feeling of disappointment upon both parents, and when Pan Xiang turned out to be a boy with special needs, the mother could have felt even more unsuccessful. On the other hand, the grandmother who thought that the child just had to be taken out more frequently could also cause a feeling of guilt.

This lack of self-confidence translated itself in different ways. Two were directly observable. On the one hand the mother refused to stand in front of the class with her child, and even repeated encouragement of teacher and other parents could not help. On the other hand this lack of self-confidence was transferred onto the child, who repeatedly said he did things wrong, even if he was told he did alright. Other ways of conduct, like the fear of loss of face, can be interpreted as the same lack of self-confidence.

When looking at the demands made on Pan Xiang, a contradiction is noticeable. When observing classes when parents and children had to work together, e.g. arts class, it seemed that the expectations were rather low. Whenever possible, mother or tutor would do Pan Xiang's tasks. When Pan Xiang had to make a drawing, it was the mother who drew a house. When, in another class, Pan Xiang had to play cards, the mother laid the cards that Pan Xiang was allowed to hold. On neither moment there had been a chance for Pan Xiang to show off his skills. Also in the interview the mother explained to have no other expectations than having her son growing up a normal child, which on the one side seems to show that there are no high expectations, but on the other side also shows the unaccepted disability.

In contradiction, when Pan Xiang had to perform individually in front of the class, during parent's operation classes or test moments, it seemed the expectations were rather high. Every task had to be performed correctly for a rather long time before there was given any form of reinforcement. Praises were given on a very low level, although there was never any disapproval of wrong conduct of the child while being in class<sup>196</sup>.

---

<sup>194</sup> This has numerous reasons, like media reports about autism being caused by a lack of parental love (mother of Zhang Dingqi), or fearing that there was too much emphasis on studying when the child was still very young, (Zhen (2000), p. 16) among others.

<sup>195</sup> This, also, has numerous reasons, like the child being diagnosed too late (see 4.2.2.3) and the long waiting list at Xingxingyu (Sun Zhongkai).

<sup>196</sup> The fact that Pan Xiang said himself to be wrong points out that there was some form of disapproval of false behavior outside of class, as confirmed by the home tutor.

Even when the teacher asked to keep the tasks simple, the orders given were always rather advanced. For instance, when the teacher said it was alright to just let Pan Xiang clap his hands, the tutor still asked him to clap his hands and afterwards stamp his feet. Of course, it has to be noted that there was a tutor involved who was used teaching children in normal education classes and thus might have rather high expectations of her pupil, but observations made clear that the mother had no other expectations than the teacher had. This became obvious through the learning materials bought and the frequency of learning activities.

#### 7.2.2.2 Li Jiaxun 李佳逊

**Background:** Li Jiaxun is a six-year-old boy, who attended Xingxingyu with both his mother and father. While the mother normally worked, and had to take a leave to attend Xingxingyu, the father had been unemployed for over three years. The family lived in Heilongjiang, together with three other uncles (paternal side). Li Jiaxun had no siblings.

Before the age of two, his mother said Li Jiaxun to have a rather normal development. He could say some single words like “mother” and “father” and seemed to understand the orders given. When he passed the age of two this ability seemed to have disappeared. Li Jiaxun did not utter any words any more, nor did he react on any orders given or any words spoken. At the age of three and a half his parents took him to the hospital where the doctors did a physical check up, including hearing tests, which did not show any results. The doctor opted there was a chance the child was autistic and after some additional tests this was confirmed. After the diagnosis, they found out about Xingxingyu and signed up to be enrolled in the program.

Li Jiaxun stayed at home during the time between signing up and entering Xingxingyu. He learned how to speak some single words again and learned how to write them, but he had no sense of communication. His language was limited to repeating words said by others, or characters he had read somewhere. When he saw a character he would remember how to write it, something he loved to do.

**Xingxingyu:** The mother of Li Jiaxun seemed to be content with the training received. She found herself and her child to have improved, as was confirmed by the teacher.

Li Jiaxun and his parents seemed to have a special position in class. Li Jiaxun was seen as the most difficult but brightest child. He had a more advanced use of language and was able to do every task properly. This made other parents admire Li Jiaxun. Sometimes there was even some form of competition when other children were pushed to do the same as

Li Jiaxun had<sup>197</sup>. The boy was also feared by the other parents though, especially when parent's operation classes and test moments had to be conducted with different children. Li Jiaxun was stubborn and did not cooperate with anyone except his own mother. He was afraid of strangers and when other parents tried to train him he would start crying or throw his learning materials away.

His parents had obtained this special position in class also because of their difficult child. They were awarded the best parents in class<sup>198</sup>, and other parents sometimes asked advice. Also, the father was always taking care of different children during classes, helping those mothers who were accompanying their child alone.

The mother also thought she did a good job, but she claimed it was hard on her because the child was so difficult to train. Except for this, she also thought her child had good abilities when compared to the other children in class.

**Attending Class:** While both parents accompanied the child, it was always the mother who trained Li Jiaxun during test moments or parent's operation classes. The father only trained the child during the morning exercises. Since it was the father of this family who was unemployed, it was not clear why the father did not train the child more often. Probably this was just a mutual agreement, although teachers at Xingxingyu want mothers to participate the most, as was said by Xie Yuqin.

Although the mother made a rather shy appearance, certainly when she was in charge of snack/fruit times, she also seemed very confident. This feeling increased noticeable after she was chosen best parent of the class. While conducting parent's operation classes, both with Li Jiaxun and other children, she was not afraid to stand in front of the class and show off her skills. She also was the only parent who would give suggestions to other parents after their session during parent's operation classes.

When she was training Li Jiaxun in class, she stuck to exercises prescribed, even though she sometimes thought her child could do better. Her child could, for instance, utter a lot of words, still he had to do some pronunciation exercises to make him say words without repeating them.

---

<sup>197</sup> One example was observed when the mother of Pan Xiang tried to make her child write characters, as Li Jiaxun had, although Pan Xiang was never observed to have written characters before.

<sup>198</sup> Xingxingyu awards the two best parents of every class with money. The teachers can choose how they select who has improved the most, and in the class observed it were the parents who did the selection. However, when the Li family was selected, they said not to need the money and thus the class selected another parent.

When Li Jiaxun performed correctly, he would be praised and after a few times, or when he did not cooperate anymore, would be reinforced. Reinforcements were clearly matched on the child, e.g. playing his favourite game or giving him the time to write some characters. When Li Jiaxun, for instance, threw his learning materials away, this was ignored, as taught by the teacher.

During classes where parents and children had to work together, e.g. arts class, Li Jiaxun was often allowed to work alone. The parents did have some expectations though, like writing his name on his drawing or saying the names of his classmates before allowing him to write some characters again, but when Li Jiaxun did not act accordingly he was mostly left alone. The teacher said this child to be the only child in class not helped by the parents with tasks they knew he was capable of.

During the interview the mother said she wanted her child to attend a normal education school and said to believe her child liked attending classes. She claimed to not have any other special expectations. Being aware of the fact that parents will probably not reveal all their hopes, it has to be pointed out that the observations did not show any other special expectations either. Both parents knew the abilities of the child and exercises were accordingly, thus developing the child's abilities without overestimating its skills.

**Conclusions:** Again, some individual conclusions can be drawn. Firstly, it has to be noted how different this family is from Pan Xiang's family. Not only did both Li Jiaxun's parents come to Xingxingyu, the expectations and how those expectations showed differed. Li Jiaxun was asked to do those things he was clearly capable of, but when he failed this was ignored. Never were any observations made of the mother losing her temper or bluntly telling the child it was wrong.

Also, the mother showed a lot of self-confidence. She did not mind getting in front of the class or speak up, and she said to be confident about her own skills. Although Li Jiaxun seemed to be quite indifferent to the praises and reinforcements received, he did not show any signs of feeling inferior either. Also, he was very close with his parents, which he showed by obeying them, something he did not do with other parents, or with the teacher.

Secondly, there were some clear expectations towards the child, but they did not seem too high or too low. The abilities of the boy were known, and both parents did not appreciate the child to not perform accordingly, but he did not have to do more than he could. For instance, although he could read characters he was never asked to read, or write, full sentences. This can be regarded either as a good or a bad thing. On the one hand this shows

the acceptance of the parents towards the disability of their child, on the other hand this could be interpreted as not stimulating the child to learn new things. Since the teacher claimed that Li Jiaxun was the child that had made the most improvement in class, this seemed not to be a disadvantage.

Thirdly, after the diagnosis was made, the parents did not make any efforts to get the child cured. Li Jiaxun did not have any acupuncture treatment nor any other form of hospital treatment. On the contrary, his parents searched a training centre right away. One of the reasons could be that Li Jiaxun was very sensitive to the smell in hospitals, as said by his mother, but another reason could be the acceptance of the autistic child. As every parent, the parents of Li Jiaxun surely had some problems accepting the diagnosis at first, but when they attended Xingxingyu they seemed to have overcome those problems. This also, to some extent, explains the self-confidence of the mother.

#### 7.2.2.3 The Parents In Between

As put before, the parents discussed seem to present the two ends of a spectrum in the class observed. On the one hand there is the unconfident mother of Pan Xiang, who wants her child to be normal and act accordingly. On the other hand there is the Li family, who accepted the disability of their child, did not seem to blame themselves and were trying to make the best out of it.

Other parents observed seem to show characteristics of both families. Being unconfident was observed in a lot of families in numerous ways. While some mothers immediately lost all hope when their child made a mistake, others did not want to have their photo taken when asked by other parents. It has to be stated though that these parents could perform in front of the class without too many problems.

When parents were observed on the expectations they had towards their child, the dichotomy as seen in the example of Pan Xiang was often perceived. Parents wanted their children to do their utmost, but all tasks were almost exclusively done by the parents - when the teacher let them - although some parents would inform the teacher about the developments made by their child. Also, they would agree with the teacher that improvements were made, and new goals were achieved.

Praising the child for what it could do was hard on almost every parent, which shows that accepting the child being autistic was not always evident. Some parents had a very hard time smiling to their child, giving appropriate reinforcement or praising it. The frequency of praising or reinforcing the child differed from parent to parent, but basically it seemed to be

easier to praise other children than praising one's own. The latter seemed to be likewise for all parents. It was easier to be happy about the little achievements made by other children, than being happy about the achievements made by their own child.

## **8. Conclusion**

When starting to address the topic ‘autism in China’, I was aware that I was touching on an amalgam of subjects. These subjects will be discussed separately below, in an attempt to provide the reader with some final thoughts.

### **8.1 Autism**

Even without considering the phenomenon of autism in a specific society, it is remarkable to what extent autistic individuals and their relatives form their own culture. The fact that these people form a particular culture is related to the specific character of the disorder.

Firstly, autism is not a visible disorder, but a so-called hidden disorder. Autistic children are often described as beautiful, quiet children, who do not at all look disabled. In one way, this could be considered a disadvantage, because it leaves parents and grown up individuals with autism feeling misunderstood. People who are not in frequent touch with an autistic child, could be wondering why parents think of their child as developmentally delayed, let alone disabled. This is certainly different for individuals who are visibly disabled.

Secondly, the fact that autism is a developmental disorder, with an early offset, is an important aspect as well. Autistic children have a very short period of normal development, if at all. For the parents this means they always saw their child as a problem child. From infancy on, they worried about their child’s eating problems, sleeping problems, motor dysfunctions and so on. This is an important aspect, because parents compare their children to normal-developing peers, and all they see is difference. On top of this, some recollect their child as being different from infancy on, in contradiction to parents whose children became disabled when older. This is important when considering the parent-child relation.

### **8.2 Autism in China**

Compared to the West, China has a considerable short history regarding autism. The autism situation was already developing for 40 years in the West, before Tao Guotai reported the first case in China. During these 40 years, the Western autism culture had already gone through some changes.

In this regard, it has to be mentioned that Western autistic individuals in the seventies also had great difficulties in obtaining a diagnosis and getting access to services. Gunilla Gerland learned about herself being autistic by reading books about autism. When she was in

her twenties, a doctor verified her assumption.<sup>199</sup> Dominique Dumortier noted down all her symptoms when she was 24 in order for a doctor to diagnose her<sup>200 201</sup>.

It could be suggested that China is actually doing better, probably because of the know-how imported from the West. Twenty years after the first diagnosis, children are diagnosed, with the help of their parents, during childhood. Still, due to specific thoughts about disability and a lack of knowledge on autism from laymen, autistic families encounter particular problems.

Because it is impossible to touch on all different aspects of society, it was chosen to study education for autistic children in scrutiny. Hereby it became possible to look at the problems encountered by autistic individuals and their families. It is conceivable that the problems concerning education are also noticeable in other elements of society, e.g. labour market.

### **8.2.1 Education**

Education is a good way to get an insight in how the autism culture functions in China, because it involves different actors and settings, and thus different views, which have to cooperate in one way or another.

First, laws, in the sense that legislative measures are taken to decide who has the right to be educated, control education. Second, there are people who have to implement these laws, e.g. principals and educators. Third, parents are also involved, as they advocate that their children receive education. These three ‘actors’ are all embedded in Chinese society but have their specific positions, rights and obligations as well.

In general, laws allow disabled children to receive education. Also, there is a choice between special and normal education. Therefore, it could be argued that every disabled child is able to receive education, adapted to its specific abilities and needs. Still, the generality of these laws results in autistic children getting excluded or hindered from an appropriate form of education.

Firstly, these laws do not specifically mention or define autism, leaving those who have to implement the law with the freedom to neglect this kind of children. Secondly, parents do not seem to consider their child’s specific disorder. This partly is because there are few clear-cut services available, and because parents have to seek those services themselves.

---

<sup>199</sup> Gerland (2005), pp. 190-195.

<sup>200</sup> Dumortier (2002), pp. 9-16.

<sup>201</sup> Of course, individuals who were more severely autistic could be diagnosed earlier, but still this comparison is justified because this thesis mostly deals with mildly autistic children.



Therefore, parents want their children to get educated in normal education schools, as they feel this is the only possibility. On top, they try to prepare their children to be a normal student, which is visible in the parent-child relation.

### **8.2.2 The Parent-Child Relation**

Even parents of autistic children know little about what autism actually contains. What these parents know is that surviving as an autistic individual in Chinese society is difficult. Therefore, they are pushed - both by themselves and their surroundings - to make their child act normal.

This is very observable in the parent-child relation, even when parents are in an environment where they are pushed to perceive the qualities of their children, e.g. Xingxingyu. In this regard, it is remarkable how deep-rooted thoughts concerning disability, parenting, and 'leading a good life' are. Still, it cannot be forgotten that parents act as a child's most important advocates, and that the positive evolution observable in China today has a great deal to do with advocating parents. In this regard two tendencies have to be pointed out.

On the one hand, an increasing amount of parents set up private organizations in order to help people with the same problems. On the other hand, parents persist more and more in letting their child receive education in an individual way. These two tendencies influence each other. Not only do organizations like Xingxingyu try to make parents see both the abilities and disabilities of their child, parents are also strengthened by positive stories of other parents.

### **8.3 A Personal Note**

Writing a thesis can be a very interesting task if it can be written on a topic where the student is particularly interested in. Since I was able to combine two of my biggest points of interest, it was no doubt very instructive. Still, before I started to do my actual research at Xingxingyu, I had no clue of how interesting it would get. Getting the chance to do this kind of research and learn more about this topic through personal stories was especially interesting. I am therefore grateful to have had a chance to do this, and can state that those stories, the interaction with individuals and the friendships built are precious gifts, which will not be forgotten.

## Appendices

### 1. Details of the Interviews

Below, the details of the interviews are listed. After the name, some background information on every interviewee is given. All this data is listed as obtained in the summer of 2005. Also, the exact date and time of each interview is listed. If there are any remarks worth mentioning, this is also added below.

#### **1.1 Parents**

1. Mother of Xiaohu 小呼, 33 years old, coming from Inner Mongolia.  
Xiaohu, a boy, is 8 years old and attends the *tigao ban* 提高班, since he has been in Xingxingyu once before.  
Interviewed on 12-09-2005 from 9 a.m. to 9.30 a.m.  
The name has been changed.
2. Father of Wang Yilin 王一霖, 32 years old, coming from Heilongjiang.  
Wang Yilin, a boy, is 6 years old and attends the *tigao ban*, since he has been in Xingxingyu once before.  
Interviewed on 12-09-2005 from 10.30 a.m. to 11.30 a.m.
3. Mother of Pan Xiang 潘祥, coming from Guangdong.  
Pan Xiang, a boy, is 6 years old and attends *shao yi ban* 少一班, the class with children with moderate abilities.  
Interviewed on 13-09-2005 from 9 a.m. to 9.50 a.m.  
The interview has not been taped.
4. Mother of Li Jiaxun 李佳逊, 30 years old, coming from Heilongjiang.  
Li Jiaxun, a boy, is 6 years old and attends *shao yi ban*.  
Interviewed on 13-09-2005 from 10.30 a.m. to 11 a.m.
5. Mother of Zhang Zhiyu 张之宇, 32 years old, coming from Shanxi.  
Zhang Zhiyu, a boy, is 6 years old and attends *shao er ban* 少二班, the class with children with better abilities.  
Interviewed on 14-09-2005 from 6.15 p.m. to 6.45 p.m.
6. Mother of Dong Nan 董楠, 35 years old, coming from Shanxi.  
Dong Nan, a girl, is 9 years old and attends the *tigao ban*, since she has been in Xingxingyu three times before.  
Interviewed on 14-09-2005 from 7.15 p.m. to 8 p.m.

7. Mother of Li Jiachen 李嘉琛, 32 years old, coming from Hebei.  
Li Jiachen, a boy, is 7 years old and attends *shao yi ban* as a “visitor” (*guanmo* 观摩), which means he cannot participate in every lesson and is not supposed to stay for the whole semester.  
Interviewed on 15-09-2005 from 6.15 p.m. to 6.45 p.m.
8. Mother of Gao Zihao 高子昊, 31 years old, coming from Beijing.  
Gao Zihao, a boy, is 6 years old and attends the *tigao ban*, since he has been in Xingxingyu once before.  
Interviewed on 15-09-2005 from 7.15 p.m. to 7.45 p.m.
9. Mother of Zhang Dingqi 张丁琪, 32 years old, coming from Henan.  
Zhang Dingqi, a girl, is 6 years old and attends *shao yi ban*.  
Interviewed on 16-09-2005 from 6.15 p.m. to 7.05 p.m.
10. Mother of Ruan Yugang 阮钰钢, 36 years old, coming from Hebei.  
Ruan Yugang, a boy, is 7 years old and attends *shao er ban*.  
Interviewed on 16-09-2005 from 7.15 p.m. to 7.30 p.m.  
The interview has not been taped.  
Due to external factors the interviewer ended the interview before all the questions were asked.
11. Mother of Xiaoliu 小刘, coming from Guizhou.  
Xiaoliu, a boy, is 9 years old and attends *shao yi ban*.  
Interviewed on 19-09-2005 from 6.15 p.m. to 6.40 p.m.  
The name has been changed.
12. Father of Yang Yu 杨钰, 35 years old, coming from Shanxi.  
Yang Yu, a girl, is 8 years old and attends *shao er ban*.  
Interviewed on 19-09-2005 from 7.15 p.m. to 7.40 p.m.
13. Mother of Chen Sicheng 陈思成, 35 years old, coming from Beijing.  
Chen Sicheng, a boy, is 6 years old and attends *shao er ban*.  
Interviewed on 20-09-2005 from 6.15 p.m. to 6.45 p.m.
14. Mother of Zhuang Yanjun 庄彦钧, 36 years old, coming from Fujian.  
Zhuang Yanjun, a boy, is 6 years old and attends *shao er ban*.  
Interviewed on 20-09-2005 from 7.15 p.m. to 7.45 p.m.
15. Mother of Cheng Siyuan 程思远, 33 years old, coming from Heilongjiang.

Cheng Siyuan, a boy, is 6 years old and attends *shao er ban*.

Interviewed on 21-09-2005 from 6.15 p.m. to 6.45 p.m.

16. Mother of Yin Jiajun 殷嘉俊, 41 years old, coming from Jilin.

Yin Jiajun, a boy, is 12 years old and attends *shao er ban*.

Interviewed on 21-09-2005 from 7.15 p.m. to 7.55 p.m.

## 1.2 Staff of Xingxingyu

1. Liu Wei 刘伟 is 25 years old. She has been working in Xingxingyu from

2004 on and teaches *shao yi ban*.

Interviewed on 22-09-2005 from 4.30 p.m. to 5.30 p.m.

2. Xie Yuqin 谢玉琴 is 24 years old. She has been working in Xingxingyu

from 2004 on and teaches *shao san ban* 少三班, the class with children with lesser abilities.

Interviewed on 23-09-2005 from 4.30 p.m. to 5.30 p.m.

3. Deng Xiaoling 邓小玲 is 25 years old. She has been working in Xingxingyu

from 2003 on and teaches *shao er ban*.

Interviewed on 26-09-2005 from 4.30 p.m. to 5.30 p.m.

4. Wu Liangsheng 吴良生 is 30 years old. He has been working in Xingxingyu

from 1998 on and teaches the *tigao ban*.

Interviewed on 28-09-2005 from 4.30 p.m. to 5.30 p.m.

5. Tian Huiping 田惠平 is 50 years old. She established Xingxingyu in 1993 and is the principal ever since.

Interviewed on 29-09-2005 from 10 a.m. to 11 a.m.

## 2. List of Hospitals Able to Provide a Formal Diagnosis

This list is provided by Xingxingyu and is an incomplete overview of hospitals where a formal diagnosis of autism can be obtained.

### 2.1 Beijing

- Beijing daxue fushu di liu yiyuan (Jingshen weisheng yanjiusuo) 北京大学附属第六医院 (精神卫生研究所)

## **2.2 Guangdong**

- Guangzhou Zhongshan yixueyuan fushu san yuan 广州中山医学院附属三院
- Guangzhoushi fuyou baojianyuan 广州市妇幼保健院
- Shenzhen ertong yiyuan Fujian Fuzhou xiehe yiyuan 深圳儿童医院福建福州协和医院

## **2.3 Hubei**

- Hubei yixueyuan fushu yixueyuan 湖北医学院附属医学院

## **2.4 Hunan**

- Hunansheng ertong yiyuan shenjing neike 湖南省儿童医院神经内科
- Hunan yike daxue di er fushu yiyuan 湖南医科大学第二附属医院
- Hunan Changsha Zhongguo qingshaonian ertong weisheng zhongxin 湖南长沙中国青少年儿童卫生中心

## **2.5 Guangxi**

- Guangxi yike daxue di yi fushu yiyuan 广西医科大学第一附属医院
- Guangxi Liuzhou Longquanshan yiyuan 广西柳州龙泉山医院

## **2.6 Shandong**

- Shandongsheng jingshen weisheng zhongxin 山东省精神卫生中心
- Qingdao yixueyuan fushu yiyuan erke 青岛医学院附属医院儿科

## **2.7 Sichuan**

- Chongqing yike daxue fushu yiyuan 重庆医科大学附属医院
- Huaxi yike daxue fushu yiyuan 华西医科大学附属医院

## **2.8 Shanghai**

- Shanghai xinli zixun zhongxin 上海心理咨询中心

## **2.9 Jiangsu**

- Nanjing jingshen weisheng yanjiu zhongxin 南京精神卫生研究中心

## **2.10 Henan**

- Zhengzhoushi ertong yiyuan 郑州市儿童医院

## **2.11 Heilongjiang**

- Heilongjiangsheng jiankang yiyuan 黑龙江省健康医院

## **2.12 Jilin**

- Jilinsheng Sipingshi jingshenbing yiyuan 吉林省四平市精神病医院
- Changchun yike daxue di er fushu yiyuan 长春医科大学第二附属医院

## **2.13 Liaoning**

- Shenyang yike daxue fushu yiyuan 沈阳医科大学附属医院
- Shenyang ertong yiyuan xinlike 沈阳儿童医院心理科

## **2.14 Shaanxi**

- Xi'an Jiaotong daxue di er yiyuan xingwei fayu erke yanjiushi 西安交通大学第二医院行为发育儿科研究室

## **2.15 Xinjiang**

- Xinjiang di er renmin yiyuan erke 新疆第二人民医院儿科

## **2.16 Tianjin**

- Tianjin ertong yiyuan 天津儿童医院

## **2.17 Hebei**

- Shijiazhuang ertong yiyuan 石家庄儿童医院

### **3. List of Institutes Connected to Xingxingyu**

Below, the institutes who were involved in the Xingxingyu training network in the summer of 2005 are listed. Some of them have been discussed in part 6.1.1. Their full name is listed, together with their date of foundation. When available, their website is submitted, although it has to be noted that Chinese websites tend to come and go.

### 3.1 Guangdong

- Guangzhoushi Baiyunqu xiaotaiyang teshu ertong kangfu zhongxin 广州市白云区小太阳特殊儿童康复中心, 1994,  
[www.0086e.com/webease/auto/Templet/24/company.asp?Userid=11593](http://www.0086e.com/webease/auto/Templet/24/company.asp?Userid=11593).
- Guangdongsheng yang ai teshu haizi jiaozhang julebu 广东省扬爱特殊孩子家长俱乐部, 1997, [www.parentclub.ngo.cn](http://www.parentclub.ngo.cn).
- Guangzhoushi Haizhuqu huanledao ertong xunlianyuan 广州市海珠区欢乐岛儿童训练园, 2001, [www.gzhld.net](http://www.gzhld.net).
- Shenzhenshi zibizheng yanjiuhui 深圳市自闭症研究会, 2001, [www.sas.org.cn](http://www.sas.org.cn).
- Foshanshi qifei jiaoyu zixun youxian gongsi 佛山市启扉教育咨询有限公司, 2003, [www.fsqifei.com](http://www.fsqifei.com).
- Guangzhou rongqun jiaoyu zixun youxian gongsi 广州融群教育咨询有限公司, 2003.
- Guangzhoushi Panyu yu jiaole jiaoyu zixun fuwu gongsi 广州市番禺寓教乐教育咨询服务公司, 2004.
- Huizhoushi humiao ertong fazhan zhongxin 惠州市护苗儿童发展中心, 2003, [www.hzhm.net](http://www.hzhm.net).

### 3.2 Jilin

- Jilinsi Fengmanqu peizhi zhongxin xuexiao 吉林市丰满区培智中心学校, 1994.
- Changchunshi xingguang teshu ertong xunlian yanghu zhongxin 长春市星光特殊儿童训练养护中心, 2003.

### 3.3 Liaoning

- Fushunshi ertong ganjue tonghe xunlian zhongxin 抚顺市儿童感觉统合训练中心, 1998.

### 3.4 Shandong

- Zhongguo beifang bo'ai kangfu zhongxin 中国北方博爱康复中心, 1998.
- Qingdaoshi Shibei qu zibizheng yanjiuhui 青岛市市北区自闭症研究会, 2000, [www.elimautism.org](http://www.elimautism.org).

- Ji'nanshi mingtian ertong kangfu zhongxin 济南市明天儿童康复中心, 2003, [www.cngudu.net](http://www.cngudu.net).

### **3.5 Hunan**

- Hunan aimi'er teshu ertong jiaoyu zhongxin 湖南爱弥尔特殊儿童教育中心, 1999, [www.tejiao.com](http://www.tejiao.com).
- Hunansheng Zhuzhoushi jiazhang zhiyuan zhongxin 湖南省株洲市家长支援中心, 2003.
- Hunansheng Zhuzhoushi ertong fuliyuan ren'ai ertong fazhan zhongxin 湖南省株洲市儿童福利院仁爱儿童发展中心, 2004, [www.zzety.com](http://www.zzety.com).

### **3.6 Shaanxi**

- Lalashou zhizhang renshi kangfu zhiyuan zhongxin 拉拉手智障人士康复支援中心, 2001, [www.lalashou.org/lisnews/default.asp](http://www.lalashou.org/lisnews/default.asp).

### **3.7 Hebei**

- Cangzhoushi "ganlanshu" ertong qianneng kaifa zhongxin 沧州市“橄榄树”儿童潜能开发中心, 2002.

### **3.8 Heilongjiang**

- Heilongjiangsheng Daqingshi jiaming teshu ertong fazhan yanjiu zhongxin 黑龙江省大庆市嘉铭特殊儿童发展研究中心, 2002.
- Mudanjiangshi qimingxing jiaoyu yanjiusuo 牡丹江市启明星教育研究所, 2003.

### **3.9 Jiangsu**

- Nanjing mingxin guduzheng ertong jiankang zixun zhongxin 南京明心孤独症儿童健康咨询中心, 1998, [www.njmx.org](http://www.njmx.org).
- Jiangsusheng Changzhoushi canjiren kangfu zhongxin 江苏省常州市残疾人康复中心, 2002.



### **3.10 Fujian**

- Fujiansheng Yong'an shi xinyu ertong xingwei ganyu zhongxin 福建省永安市心语儿童行为干预中心, 2003.
- Xiamen Jia'nán shào'ér pèixùn zhōngxīn 厦门迦南少儿培训中心, 2003, [www.xmcanaan.com](http://www.xmcanaan.com).
- Quanzhou Beidouxing ertong fazhan zhongxin 泉州北斗星儿童发展中心, 2004.

### **3.11 Guangxi**

- Guangxi Liuzhou jiazhang zhiyuan zhongxin 广西柳州家长支援中心, 2003.

### **3.12 Guizhou**

- Guizhousheng yiyangren teshu ertong kangfu zhongxin 贵州省一样人特殊儿童康复中心, 2003.

### **3.13 Hainan**

- Haikou shileyuan zibizheng xuexiao 海口施乐园自闭症学校, 2003.

### **3.14 Gansu**

- Lanzhoushi teshu ertong jiazhang zhiyuan zhongxin 兰州市特殊儿童家长支援中心, 2003.

### **3.15 Shanghai**

- Shanghai xingyu ertong kangjianyuan 上海星雨儿童康健院, 2003, [www.shanghaiautism.com](http://www.shanghaiautism.com).

### **3.16 Tianjin**

- Tianjin menggongchang ertong zhuzhang zhongxin 天津梦工厂儿童助长中心, 2003.

### **3.17 Jiangxi**

- Jiangxi Jiujiangshi xinyuxin teshu jiaoyu jigou 江西九江市心语心特殊教育机构, 2004, [www.xyux.com](http://www.xyux.com).

## **Bibliography**

*A Chinese-English Dictionary (Revised Edition)*, *Hanying cidian* 汉英词典, Beijing: Foreign Language Teaching and Research Press, 1997.

Arms, K., "Stars Through the Rain", *Unesco Courier* 53:1 (2000), p. 23.

Billiet, J. & H. Waege, *Een samenleving onderzocht: Methoden van sociaal-wetenschappelijk onderzoek*, Antwerpen: Standaard, 2001.

Bowes, J., M.J. Chen, Q.S. Li & Y. Li, "Reasoning and Negotiation About Child Responsibility in Urban Chinese Families: Reports from Mothers, Fathers and Children", *International Journal of Behavioral Development* 28:1 (2004), pp. 48-58.

"Canjiren jiaoyu tiaoli" 残疾人教育条例 [Regulations for Schooling of Disabled People], *New Law and Regulations Monthly* (1994:11), pp. 7-15.

"Canjiren shiyong pingding biaoqun" 残疾人实用评定标准 [Practical Evaluation Standard for the Disabled], 6 pp., retrieved on 19-04-2006 from:

[www.cdpe.org.cn/zhengce/xg-zl-006b.htm](http://www.cdpe.org.cn/zhengce/xg-zl-006b.htm)

Chao, R.K., "Beyond Parental Control and Authoritarian Parenting Style: Understanding Chinese Parenting Through the Cultural Notion of Training", *Child Development* 65 (1994), pp. 1111-1119.

Chen, Y.Y., "Making Special Education Compulsory and Inclusive in China", *Cambridge Journal of Education* 26:1 (1996), pp. 47-58.

Clark, E. & Z. Zhou, "Autism in China: From Acupuncture to Applied Behavior Analysis", *Psychology in the Schools* 42:3 (2005), pp. 285-296.

"Cong dianying 'canghai chizi xin' tanqi" 从电影《沧海赤子心》谈起 [Beginning Talks From the Movie 'canghai chizi xin'], *Xingxingyu tongxun* 星星雨通讯 (1998:12), pp. 20-23.

Daens, M. & I. Van Elzaker, *Gestrand op een eiland van eenzaamheid: Dagboek van een vader over zijn autistische zoon*, Antwerpen: Icarus, 1997.

Davin, D., "The Early Childhood Education of the Only Child Generation in Urban China", in Epstein, I. (ed.), *Chinese Education: Problems, Policies, and Prospects*, New York/London: Garland Publishing, 1991, pp. 42-65.

De Clercq, H., *Autisme van binnen uit: Een praktische gids*, Antwerpen: Houtekiet, 2005.

Deng, M. & G. Manset, "Analysis of the 'Learning in Regular Classrooms' Movement in China", *Mental Retardation* 38:2 (2000), pp. 124-130.

Deng, M., K.F. Poon-McBrayer, E. Farnsworth & H. McCabe, “The Development of Special Education in China: A Sociocultural Review”, *Remedial and Special Education* 22 (2001), pp. 288-298.

Dumortier, D., *Van een andere planeet: Autisme van binnen uit*, Antwerpen/Amsterdam: Houtekiet, 2002.

“Family Care Helps Mentally Ill Youngsters”, *China Daily* 14 Jan. (2002), retrieved on 04-11-2005 from: [www.china.org.cn/english/SO-e/25210.htm](http://www.china.org.cn/english/SO-e/25210.htm).

Fang Jing 方静, “Yiwei Qingdao muqin de qingsu” 一位青岛母亲的倾诉 [The Tellings from a Mother of Qingdao], *Xingxingyu tongxun* 星星雨通讯 (2000:17), pp. 13-17.

Fang Jing 方静, “Jiazhang xinli lucheng san bu qu” 家长心理路程三步曲 [A Parent’s Mental Journey in Three Steps], *Xingxingyu tongxun* 星星雨通讯 (2001:24), pp. 16-18.

Frith, U., *Autism: Explaining the Enigma*, Oxford: Blackwell, 1989.

Frith, U., *Autisme: Verklaringen van het raadsel*, trans. K. Innekens, Antwerpen: EPO, 2003.

“Gao jiazhang” 告家长 [Telling Parents], *Xingxingyu tongxun* 星星雨通讯 (1996:1), p. 17.

Gerland, G., *Een echt mens: Autobiografie van een vrouw met autisme*, trans. L. Keustermans, s.l.: Pandora, 2005.

Grandin, T., “An Inside View of Autism”, 19 pp., retrieved on 13-02-2006 from: [www.autism.org/temple/inside.html](http://www.autism.org/temple/inside.html).

“Guduzheng jiazhang tan (2)” 孤独症家长谈 (二) [Talks of Parents of Autistic Children (2)], *Xingxingyu tongxun* 星星雨通讯 (1997:7-8), pp. 45-52.

Gu Xiuhui 谷秀慧, “Fang Jing yu Yilin Zibi’ertong Kangfu Zhongxin” 方静与以琳 自闭儿童康复中心 [Fang Jing and the Yilin Rehabilitation Centre for Autistic Children], *Tianfeng* 天风 (2003:7), pp. 28-29.

“Guanyu kaizhan canji ertong shaonian suiban jiudu gongzuo de shixing banfa” 关于开展残疾儿童少年随班就读工作的试行办法 [Methods of Launching the Work of *Suiban Jiudu* for Children and Youth], 4 pp., retrieved on 19-11-2005 from: [www.cosn.net/htm/class/ordinance/2004-09-01-10853.htm](http://www.cosn.net/htm/class/ordinance/2004-09-01-10853.htm).

Hermelin, B., *Bright Splinters of the Mind: A Personal Story of Research with Autistic Savants*, London: Kingsley, 2001.

Ho, D.Y.F., S.Q. Peng & A.C. Lai, "Parenting in Mainland China: Culture, Ideology, and Policy", *International Society for the Study of Behavioural Development Newsletter* 38 (2001), pp. 7-9.

Ji, G.P., S.H. Jiao & Q.C. Jing, "Expectancy of Chinese Parents and Children's Cognitive Abilities", *International Journal of Psychology* 28:6 (1993), pp. 821-830.

Kleinman, A., W.Z. Wang, S.C. Li, X.M. Cheng, X.Y. Dai, K.T. Li & J. Kleinman, "The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China", *Social Science & Medicine* 40:10 (1995), pp. 1319-1330.

Kohrman, M., "Grooming *que zi*: Marriage Exclusion and Identity Formation Among Disabled Men in Contemporary China", *American Ethnologist* 26:4 (1999), pp. 890-909.

Kohrman, M., *Bodies of Difference: Experiences of Disability and Institutional Advocacy in the Making of Modern China*, Berkely/Los Angeles/ London: University of California Press, 2005.

Lai, A.C., Z.X. Zhang & W.Z. Wang, "Maternal Child-Rearing Practices in Hong Kong and Beijing Chinese Families: A Comparative Study", *International Journal of Psychology* 35:1 (2000), pp. 60-66.

Landschip & L. Modderman, *Dubbelklik: Autisme bevraagd en beschreven*, Antwerpen: EPO, 2004.

Lauwers, C., *Gewoon een jongen met autisme*, Antwerpen: EPO, 2004.

Lee, W.Y., "One Therapist, Four Cultures: Working with Families in Greater China", *Journal of Family Therapy* 24 (2002), pp. 258-275.

Lew, W.J.F., *Understanding the Chinese Personality: Parenting, Schooling, Values, Morality, Relations, and Personality*, New York: The Edwin Mellen Press, 1998.

"Li Jinglin fuqin de hua" 李景琳父亲的话 [The Words of the Father of Li Jinglin], *Xingxingyu tongxun* 星星雨通讯 (1997:7-8), pp. 34-36.

Lin, T.Y. (ed.), *Chinese Societies and Mental Health*, Hong Kong: Oxford University, 1995.

Liu Song 刘颂, "Beijing diqu peizhi xuexiao jiazhang he jiaoshi dui jiazhang canyu de taidu yanjiu" 北京地区培智学校家长和教师对家长参与的态度研究 (The Attitude of Parents & Teachers toward Parent Involvement in Special Schools for MR), *Zhongguo teshu jiaoyu* 中国特殊教育 31:3 (2001), pp. 11-16.

Lovaas, O.I., “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children”, *Journal of Consulting and Clinical Psychology* 55:1 (1987), pp. 3-9.

Lu Hailian 陆海莲, “Aixin puchu chengzhanglu – yige guduzheng ertong jiazhang de ganwu” 爱心铺出成长路——一个孤独症儿童家长的感悟 [Kindness Paves the Way to Adulthood – The Comprehensions of the Parent of an Autistic Child], *Shandong jiaoyu* 山东教育 (2005:18), pp. 40-41.

Lü Xiaotong 吕晓彤 & Gao Qiaozhi 高桥智, “Zibizheng ertong muqin zai yangyu ertong guocheng zhong de xuqiu diaocha” 自闭症儿童母亲在养育儿童过程中的需求调查 (A Survey on the Support Needed by Mothers of Autistic Children in China), *Zhongguo teshu jiaoyu* 中国特殊教育 61:7 (2005), pp. 47-53.

Ma Tao 马韬, “Shenghuo zai ling yige shijie” 生活在另一个世界 [Living in Another World], *Xinwen zhoukan* 新闻周刊 (2003:16), pp. 54-59.

McCabe, H., “The Beginnings of Inclusion in the People’s Republic of China”, *Research and Practice for Persons with Severe Disabilities* 28:1 (2003), pp. 16-22.

McCabe, H., & H.P. Tian, “Early Intervention for Children with Autism in the People’s Republic of China: A Focus on Parent Training”, *The Journal of International Special Needs Education* 4 (2001), pp. 39-43 (26 par.). [Received from the author as a word-document]

McCabe, H., S.X. Wu, & G.J. Zhang, “Experiences with Autism in the People’s Republic of China: Viewing Social Change Through One Family’s Story”, *The Journal of International Special Needs Education* 8 (2005), pp. 11-18 (46 par.). [Received from the author as a word-document]

McLoughlin, C.S., Z. Zhou & E. Clark, “Reflections On the Development and Status of Contemporary Special Education Services in China”, *Psychology in the Schools* 42:3 (2005), pp. 273-282.

Merry, R., “Managing Special Needs Provision in China: A Qualitative Comparison of Special Needs Provision in the Shaanxi Region of China and England”, *Compare: A Journal of Comparative Education* 28:2 (1998), pp. 207-218. [Retrieved via EBSCOhost]

“Model of Parent-Training Program”, 1 p., retrieved on 18-07-2005 from: [www.guduzh.org.cn/english/service/004.htm](http://www.guduzh.org.cn/english/service/004.htm).

Niu Yubai 牛玉柏, Liu Zewen 刘泽文 & Tian Bao 田宝, “Jiazhang dui canji ertong suiban jiudu taidu yanjiu” 家长对残疾儿童随班就读态度研究 (Parent’s Attitude Toward Children with Disabilities Learning in Regular Class), *Zhongguo kangfu lilun yu shijian* 中国康复理论与实践 11:1 (2005), pp. 72-73.

Park, C.C., *Het beleg: De eerste acht jaar van een autistisch kind*, trans. D. Dijkstra & H. Van der Worp, Amsterdam: Ambo, 2001.

“Pioneers and Practitioners”, 2 pp., retrieved on 05-05-2006 from: [www.lovaas.com/pdf/pioneers\\_practitioners.pdf](http://www.lovaas.com/pdf/pioneers_practitioners.pdf).

Potts, P., “A Western Perspective on Inclusion in Chinese Urban Educational Settings”, *International Journal of Inclusive Education* 4:4 (2000), pp. 301-313.

Qian Zhiliang 钱志亮, “Dangjin Zhongguo teshu jiaoyu zuzhi xingshi zhi fenxi” 当今中国特殊教育组织形式之分析 (Analysis of the Form of Special Education in China), *Zhongguo teshu jiaoyu* 中国特殊教育 (1997:2), pp. 24-28.

Qiu, Z., “The Status of Training and Employment Policies and Practices for People with Disabilities in the People’s Republic of China” (draft), *International Labour Organization* (2002).

Rood, L., *Het boek Job*, Amsterdam: Prometheus, 1994.

Rubin, K., “Chinese Charities’ Long March”, *Chronicle of Philanthropy* 13:1 (2000), pp. 7-9.

“Ruozhi’er suiban jiudu shi hundu? Zhuanjia jiazhang yijian bu yi” 弱智儿随班就读是混读? 专家家长意见不一 [Is Integrating Mentally Retarded Children in Regular Classrooms Chaos? Specialists and Parents Have a Different View], 2 pp., retrieved on 14-11-2005 from: [www.cosn.net/htm/class/situation/2004-12-03-11406.htm](http://www.cosn.net/htm/class/situation/2004-12-03-11406.htm).

Sacks, O., “Een antropoloog op Mars”, in Sacks, O., *De vrouw zonder lichaam: Alle verhalen uit de praktijk*, trans. P.M. Moll-Huber, Amsterdam: Meulenhoff, 1999a, pp. 389-427.

Sacks, O., “Wondermensen”, in Sacks, O., *De vrouw zonder lichaam: Alle verhalen uit de praktijk*, trans. P.M. Moll-Huber, Amsterdam: Meulenhoff, 1999b, pp. 346-388.

Saffran, R., “What Is Applied Behavior Analysis”, 4 pp., retrieved on 14-02-2006 from: <http://rsaffran.tripod.com/whatisaba.html>.

“Semester Teaching Schedule”, 2 pp., retrieved on 18-07-2005 from: [www.guduzh.org.cn/english/service/006.htm](http://www.guduzh.org.cn/english/service/006.htm).

“Stars and Rain, Heartspring Enter Sister Organization Agreement”, 2 pp., retrieved on 04-05-2006 from: [www.guduzh.org.cn/english/sister%20school/Operation.htm](http://www.guduzh.org.cn/english/sister%20school/Operation.htm).

Stratford, B. & H. Ng, “People with Disabilities in China: Changing Outlook, New Solutions, Growing Problems”, *International Journal of Disability, Development and Education* 47:1 (2000), pp. 7-14.

“Suiban jiudu jiaoxue jihua de neirong” 随班就读教学计划的内容 [The Content of a Learning Plan of *Suiban Jiudu*], 4 pp., retrieved on 12-11-2005 from: [www.cosn.net/htm/class/teaching/2005-06-20-12462.htm](http://www.cosn.net/htm/class/teaching/2005-06-20-12462.htm).

Sun Shengtao 孙圣涛, “Guanyu zibizheng ertong jiaoyu de tantao” 关于自闭症儿童教育的探讨 [About the Exploration of Education for Autistic Children], *Shanghai jiaoyu keyan* 上海教育科研 (1998:7), pp. 31-34.

Tao Guotai 陶国泰, *Rang guduzheng ertong zouchu gudu* 让孤独症儿童走出孤独 [Let Autistic Children Walk Away from Loneliness], Beijing: Zhongguo funü chubanshe, 2005.

Tao, K.T., “Infantile-autism in China”, *Journal of Autism and Developmental Disorders* 17:2 (1987), pp. 289-296.

“The 11-Week ABA Training Course”, 1 p., retrieved on 18-07-2005 from: [www.guduzh.org.cn/english/service/005.htm](http://www.guduzh.org.cn/english/service/005.htm).

“The Lovaas Model”, 2 pp., retrieved on 05-05-2006 from: [www.lovaas.com/pdf/lovaas\\_model.pdf](http://www.lovaas.com/pdf/lovaas_model.pdf).

Tian Huiping 田惠平, “Zhongguo (dalu) guduzheng ertong shehui shengzhang huanjing zhi fenxi” 中国（大陆）孤独症儿童社会生长环境之分析 [Analysis of the Social Environment for Autistic Children Growing Up in (Mainland) China], *Xingxingyu tongxun* 星星雨通讯 (1999:14), pp. 3-6.

Tian Huiping 田惠平, “Shenme shi ABA” 什么是 ABA [What is ABA], *Xingxingyu tongxun* 星星雨通讯 (2001:21), pp. 1-3.

Vermeulen, P., *Voor alle duidelijkheid: Leerlingen met autisme in het gewoon onderwijs*, Antwerpen: EPO, 2002.

Wang Xiuqing 王秀卿, “Yi tang dianying ke” 一堂电影课 [A Movie Class], *Xingxingyu tongxun* 星星雨通讯 (1998:10), pp. 9-11.

Wei Aitang 魏爱棠, “Qunti xuqiu yu huanjing ziyuan de shiheng – guanyu minban zibizheng jiaoyu shengcun zhuangkuang de ge’an diaocha fenxi” 群体需求与环境资源的失

衡—关于民办自闭症教育生存状况的个案调查分析 (Group's Needs and Environmental Resources are Out-of-Balance – a Case Study of Non-Governmental Autism Education), *Zhongguo teshu jiaoyu* 中国特殊教育 48:6 (2004), pp. 62-66.

“What Is ABA?”, 7 pp., retrieved on 14-02-2006 from:  
[www.shapingbehavior.com/pages/3/page3.html?refresh=1138218270089](http://www.shapingbehavior.com/pages/3/page3.html?refresh=1138218270089).

“What Is a Discrete Trial?”, 2 pp., retrieved on 14-02-2006 from:  
[www.autismtreatment.info/what+is+a+discrete+trial.aspx](http://www.autismtreatment.info/what+is+a+discrete+trial.aspx).

Whitman, T.L., *The Development of Autism: A Self-Regulatory Perspective*, London: Kingsley, 2004.

Whyte, W.F., *Learning from the Field: A Guide from Experience*, Beverly Hills/London/New Delhi: Sage, 1988.

Wing, L. (ed.), *Early Childhood Autism: Clinical, Educational and Social Aspects*, Oxford: Pergamon, 1976.

Wu Guoying 吴国英, “Ta yuan yong yi sheng wei nü'er pujiu yi tiao huigui shehui de lu” 他愿用一生为女儿铺就一条回归社会的路 [He Wishes to Use His Entire Life to Lead His Daughter Back to Society], *Jiankang bi du* 健康必读 (2000:3), pp. 37-39.

“Xingxingyu chongxin kai xue” 星星雨重新开学 [Xingxingyu Starts School Again], *Xingxingyu tongxun* 星星雨通讯 (2003:31), p. 30.

“Xingxingyu fazhan shi nian da shiji” 星星雨发展十年大事记 [The Recording of Big Events During Ten Years of Development of Xingxingyu], 4 pp., retrieved on 18-07-2005 from: [www.guduzh.org.cn/chinese/liao\\_fa.html](http://www.guduzh.org.cn/chinese/liao_fa.html).

Xu Yunzhi 徐云知 & Wang Guangxue 王广学, “Shilun teshu xuexiao he suiban jiudu liang zhong tejiao xingshi” 试论特殊学校和随班就读两种特教形式 [Dealing with Special Education and *Suiban Jiudu*, Two Forms of Special Education], *Jiaoyu tansuo* 教育探索 (1997:6), pp. 27, 45.

Xue Ying 雪婴, “‘Suiban jiudu’ mo rang zhizhang'er zibe” ‘随班就读’莫让智障儿自卑 [Suiban Jiudu Does Not Make Students Have a Low Sense of Self-Esteem], 2 pp., retrieved on 14-11-2005 from: [www.cosn.net/htm/class/situation/2005-01-06-11727.htm](http://www.cosn.net/htm/class/situation/2005-01-06-11727.htm).

Yan Haihong 严海红, “Yitihua jiaoyu: suoyou ertong de xiwang” 一体化教育: 所有儿童的希望 [Inclusive Education: The Dream of Every Child], 2 pp., retrieved on 12-11-2005 from: [www.cosn.net/htm/class/teaching/2004-04-24-10051.htm](http://www.cosn.net/htm/class/teaching/2004-04-24-10051.htm).



Yan Ping 严平, “Huazuo yi ke xingxingyu – yiwei muqin he tade yi qun haizimen” 化做一颗星星雨——一位母亲和她的一群孩子们 [Becoming Stars and Rain – A Mother and her Children], *Guoji rencai jiaoliu* 国际人才交流 (1999:7), pp. 28-31.

Yang, H.L. & H.B. Wang, “Special Education in China”, *The Journal of Special Education* 28:1 (1994), pp. 93-105.

Yang, J., “Autism Receives New Attention in China”, *Beijing Review* 39:5 (1996), pp. 18-19.

“Zai Xingxingyu wo xuedao le ai” 在星星雨我学到了爱 [In Xingxingyu I Learned How to Love], *Xingxingyu tongxun* 星星雨通讯 (2002:27), pp. 24-25.

Zhang Juan 张娟, “Guanyu gaogongneng guduzheng ertong you’eryuan jiaoyu de tantao” 关于高功能孤独症儿童幼儿园教育的探讨 [On a Preschool for High Functioning Autistic Children], *Xueqian jiaoyu yanjiu* 学前教育研究 (2004:4), pp. 8-10.

Zhen Yuelai 甄岳来, “Nü’er Li Jinglin de jixue licheng” 女儿李景琳的就学历程 [The Process of Daughter Li Jinglin Attending School], *Xingxingyu tongxun* 星星雨通讯 (2000:18), pp. 16-22.

“Zhongguo suiban jiudu fazhan zhuangkuang” 中国随班就读发展状况 [The Situation of *Suiban Jiudu* in China], 2 pp., retrieved on 14-11-2005 from: [www.cosn.net/htm/class/situation/2004-04-25-10059.htm](http://www.cosn.net/htm/class/situation/2004-04-25-10059.htm).

“Zhonghua renmin gongheguo canjiren baozhang fa” 中华人民共和国残疾人保障法 [The law of the People’s Republic of China on the Protection of Persons with Disabilities], 10 pp., retrieved on 07-03-2006 from: [www.cdpf.org.cn/zhengce/fl-001.htm](http://www.cdpf.org.cn/zhengce/fl-001.htm).

Zhong, L., “Training Helps Autistic Children Emerge from Solitude”, *Women of China* (1994:6), pp. 7-8.

Zhou Jing 周兢 & Cheng Xiaoqiao 程晓樵, “Lun xueqian jiaoyu jigou zhong de teshu ertong jiaoyu” 论学前教育机构中的特殊儿童教育 [About Organizations for Pre-School Education’s Education for Special Children], *Teshu ertong yu shizi yanjiu* 特殊儿童与师资研究 (1995:3), pp. 2-5.