ARTICLE

A GOOD EXAMPLE OF PARENT ADVOCACY FOR RIGHTS IN INCLUSIVE EDUCATION IN CHINA

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Abstract While children with disabilities experience exclusion and segregation in education, parents’ involvement has been very limited due to the lack of parent support in China. Negative attitudes toward disability in an environment deeply influenced by the individual model of disability thinking makes it crucial for parents to advocate for their children’s rights in inclusive education through collaborative and organized efforts. This article examines barriers obstructing disabled children’s rights in pursuing inclusive education, barriers parents face to advocate for their children, and the development of parent support. The author argues that equal and inclusive education for all has a broader social impact beyond disability rights to eliminate barriers and pursue dignity for all. In doing so, the author reveals existing structural inequalities facing inclusive education, encourages the momentum for future changes, and utilizes a good example of parent advocacy for a deeper and meaningful policy advancement to overcome discrimination on the basis of disability that causes segregation and exclusion in education. Recommendations include strategies for the construction of a support network for parents to play their important roles in advancing the rights of their disabled children in inclusive education.

Keywords inclusive education, parent involvement, equal participation, educational rights, good practice

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INTRODUCTION

Children with disabilities have been historically deprived of their rights in education.

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In many countries, a large percent of school age children with disabilities are excluded from education. Even at the primary school level, students with disabilities, on average, experience significantly lower completion rates and fewer years of education than students without disabilities. Advocates for inclusive education in different countries have been making tireless efforts to pursue appropriate education for disabled children in settings together with students without disabilities. In the history of promoting and protecting educational rights, parents have played a critical role as the strongest and persistent advocates for their children through peer support between parents and joint efforts with educators, disability organizations, lawyers, experts, and other groups. Families of persons with disabilities provide the most immediate environment in which they can develop their potential and enjoy a life in their best interest from the very beginning of their lives. There is no doubt that the rights of persons with disabilities are directly related to the quality of life of their families. Legal reform indicates that lessons have been learned for not providing adequate systemic support to empower parents to attend to the needs of their children and, consequently, failed children with disabilities.

However, this picture of failure in the system is blurred by disability being regarded as a negative phenomenon and the source of all the problems. Through efforts of parents and other evidence-based academic support for them from academics and groups through projects, governments’ understanding of parents’ role has increased. Some governments began to provide funding support to parent organizations to duplicate the successful pilot projects and improve relevant laws and policies and the construction of infrastructure to protect the rights of parents engagement. To ensure the meaningful participation of parents, not only should parents have rights to participate in the decision making process for their children’s education, but they also need to be held accountable for participation in the process. This is a very important message both to the governing authorities and parents. For the government, urgent law and policy reform must occur in if existing laws and policies have not granted parents rights to be included in the decision making process relevant to the education of their children with disabilities, and have not defined them as critical team members in the process of evaluation, service design and delivery, placement, and assessment. For parents, they must understand, respect, and pursue the rights of their disabled children in education, acquire information, equip themselves with

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2 For example, one of the key findings revealed in a report to the former US President George W. Bush on the status of special education is that, “When a child fails to make progress in special education, parents do not have adequate option and recourse. Parents have their child’s best interest in mind, but do not feel they are empowered by the system that fails them.” See President’s Commission on Excellence in Special Education, A New Era: Revitalizing Special Education for Children and Their Families, Jul. 2002.
3 For example, in the United States’ the Individuals with Disabilities Education Act (IDEA) 2004 Amendment, parents’ rights in and responsibilities for their children’s education have been enhanced. See generally H. Ruth Turnbull, Matthew Stowe & Nancy Huerta, Free and Appropriate Public Education: The Law and Children with Disabilities (7th edition), Love Publishing Company (Denver), at Chapter 9 (2007).
the knowledge of relevant laws and policies, be responsible to educators for their children, and work closely with other sectors in the network.

I. RIGHTS IN INCLUSIVE EDUCATION AND PARENTS’ ROLE IN CHINA

In China, children with disabilities experience both exclusion and segregation in education. The inconsistence and lack of evidence-based national and local documentation on the status of education for children with disabilities makes it difficult to understand the real situation of exclusion and segregation. Whatever the accurate statistics may be, it is obvious that a certain percentage of school age children with disabilities have an opportunity to receive education in two separate systems: general education and special education. This opportunity is not available to many children with disabilities in rural areas and to most, if not all, children with severe and multiple disabilities. Efforts for rights to inclusive education promoted policy reform that allowed an increasing number of students with disabilities in general education. In principle, general and special education should share responsibilities for children with disabilities as one integrated system at all levels with individualized support to meet the special needs of each individual learner. Inclusive education has been approved to improve teaching and learning for everyone. However, in China, general and special education still operate on two parallel tracks with infrastructural barriers that make it difficult for these two systems to work together for students with disabilities in both systems. The general education system has been designed for students without disabilities and accepts a limited number of students with mild disabilities who are required to adapt to a setting in which their needs are not identified, evaluated, and accommodated. There have been inadequate, if there are any, resources and special education training for these accepted students. Therefore, those with disabilities in general education do not have special support and services to attend to their learning needs and, consequently, cannot have a meaningful learning experience. They feel new isolation, marginalization, and left behind in their learning and development. On the other hand, special education has been provided to students mainly with hearing, visual, and intellectual disabilities in segregated settings. It functions as a placement in separate settings rather than a professional service designed for an appropriate and supported education available to learners with disabilities both in separate and regular schools.

The unstructured and, therefore, unsupported education for students with disabilities is deeply rooted in the individual model of disability thinking as opposed to the social model. The former perceives disability as a tragedy and functional differences as the main source of all the problems persons with disabilities experience, while the latter perceives disability through the lenses of cultural and social factors and targets social and attitudinal

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barriers for equal rights to participation. Different models of disability approaches indicate how disability is reflected in society and how persons with disabilities are treated accordingly under the influence of these models. The individual model of thinking views persons with disabilities as “abnormal” or being fundamentally altered due to their disabilities, and thus incapable of learning, and should be treated separately as objects of charity rather than as equal citizens who can and should participate and contribute. This approach emphasizes the deficiencies of disability and implies that those who are considered “incapable” or “unproductive” should be fixed or placed in certain social welfare benefit and intervention systems if they cannot become “normal.” Shaped by this mode of thinking, society views persons with disabilities as officially disadvantaged, exempted, and excluded from so called mainstreaming. Consequently, this model ignores social and attitudinal barriers to persons with disabilities; causes exclusion and disenfranchisement of persons with disabilities and their families from policy and decision making process, which in turn denies them the opportunity to argue for their needs and claim rights, and hinders legal reform and social movement. The additional impact of the negative perspective on parenting will be discussed right after. In education, students’ disabilities have been viewed as key problems that prevent them from learning and performing in a “normal” and productive way in general education. Barriers to inclusive education, such as the negative attitudes of teachers and students, inaccessibility, rigid curriculum and instruction, unwelcoming campus culture, and so forth, have been overlooked, and even justified. Without educational reform for inclusion, students with disabilities are more likely to receive inappropriate education and services compared to their peers without disabilities. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD or Convention), which was signed and ratified by China in advance, is created on the basis of the rights/social model of disability thinking\(^5\) and urges state parties to focus on removing barriers that hinder equal participation. Disability organizations and leading parent groups have been working closely with experts to use UNCRPD as a guiding force for awareness raising and legal reform on inclusive education in China.

It is necessary to discuss the role of parents in order to understand how to provide support to them and what the consequences are for not providing the support parents need to perform their roles. Leading experts on family studies in the US point out seven basic historical roles of parents: “(1) parents or families as the source or causes of their children’s disabilities; (2) parents and families as members of family-centered, family-directed organizations that exist to satisfy families’ needs; (3) parents and families as developers of services for their children, including education, recreation, residential, and vocational services; (4) parents and families as the relatively passive recipients of professionals’ decisions, as the second (and less active) party in the principle of deference to expert opinion; (5) parents and families as the follow-through educators of their

children, as auxiliary teachers who are expected to carry out school-planned education and other interventions; (6) parents and families as political advocates, as the primary constituency behind laws... that create rights or entitlements or protection from discriminations; and (7) parents and families as education decision-makers, as partners with educators in developing plans and helping to carry out. Parents are viewed as having an emerging new role as the partners of policy-makers in collaboration with professionals. Along with the advancement of disability rights, there has been a gradually deeper understanding of parents’ roles in their children’s education moving from passive to active. This evolvement indicates a necessity for and enriched definition of the parent support system for the best interests of children with disabilities and their families.

While the UNCRPD ensures, protects, and promotes full and equal human rights of all persons with disabilities, it also addresses the role and importance of the family. An overview of UNCRPD reveals that, among fifty articles, five Articles (8, 16, 22, 23 and 28) make explicit references to families. For example, Article 8 — Awareness Raising — requires the States, “to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.”

In addition to the aforementioned problems within the education system, some major issues exist relevant to limited attention to the role of parents and a lack of systematic support for them to fulfill their roles. First, families are separated from education providers. This division hinders the coordination between schools and families and the path to carry forward what the school does to the family and community. Parents have long been a marginalized group by the school system. Culturally, teachers are the main authorities over students’ education in public education that emphasizes the traditional education model of pursuing exemplary academic performance. For children with disabilities, it is even more pronounced but in a much more complicated way, while persons with disabilities experience significant discrimination, low public awareness, and negative disability perspectives that have pervasive effects on the way parents devalue both their disabled children and also themselves for having a child with disabilities. What is more detrimental is that parenting is embedded in social and cultural contexts that influence the way parents perceive and take care of their children with disabilities. Shaped by the dominant individual model of thinking environment, parents more likely have difficulty accepting their children’s disabilities. Consequently, their negative feeling affects the ability to adopt a healthy and nourishing parenting role.

Second, parents’ role is directly related to early prevention and intervention. Evidenced-based early prevention and intervention can provide help to children with disabilities at an early age when help can be most effective. They are essential for

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7 See fn. 5 Art. 8.
children’s learning, behavior and health, contribute to later school success, and reduce the incidence of future problems. Lack of a positive, early intervention experience can cause the children to miss the most important period of development in health, language, communication, cognition, emotion, and social skills. Parents should be key players in the early intervention services their children receive. Community-based resources should be developed for high quality services for families. However, there has been very limited legal support for early intervention and families.

Third, when parents of children with disabilities are not empowered to facilitate their children’s education process, parents’ roles are limited, and so are their children’s educational outcomes. They may make wrong decisions on the child’s schooling and cannot function as equal and valued members in a partnership, which supports holistic learning for these exceptional children to achieve positive academic as well as non-academic outcomes. Some parents have been searching tediously for scattered services and support. But, because parents do not have a support system to equip themselves with the knowledge of the nature and characteristics of their child’s disabilities, their efforts might not be effective and beneficial to their children. Meanwhile, schools and educators receive inadequate information from parents about the special needs of their children. Although, in general, the family is viewed as the core unit of society, as stated in the UNCRPD, the legal foundations for parents to participate in their children’s education have not been specifically articulated in Chinese laws and policies both at the national and local levels, and is largely missing in practice.

In the past decade, international organizations aiming at promoting disability rights worldwide have realized the challenging situation for children with disabilities facing prejudice and discrimination in inclusive education and the absence of a support system for parents in China. There have been dedicated efforts to empower parents, prepare parent trainers and leaders for peer support, and enhance the development of parent groups and organizations through collaboration with Chinese experts in the field and other social groups. Projects have been designed to explore and advance the good practices of a family support network, introduce parent involvement from a comparative perspective, help parents understand their children’s rights, equip parents with advocacy skills, develop parent partnership with educators, and strengthen the professional development of parent organizations to raise awareness of parents’ roles and promote legal reform on parents’ participation. Training on the UNCRPD has been integrated in these projects to raise awareness, change attitudes, address discrimination on the basis of disability, help parents and professionals become aware of the objectives to be achieved for disabled children, and promote the understanding of domestic legal provisions and gaps in light of the UNCRPD.

These efforts have significant meaning in the Chinese context because, while the

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8 Id. Preamble(x).
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Government has a reputation for fostering the development of the UNCRPD globally; at home in China, there is large room for concrete changes to reduce inconsistencies between the UNCRPD and domestic law for promoting disability rights. It is important to emphasize that gaps can be narrowed through improving existing domestic laws and policies and their implementation, and enabling the participation of civil society, including parent groups. Training on the UNCRPD through projects mentioned above facilitated the role of the UNCRPD in raising awareness of disability rights and fighting discrimination and exclusion. To advance rights in inclusive education, concrete steps should be taken to remove systematic barriers that separate the special education from the general education system, to prepare teachers with expert knowledge on special education, and to recognize the unique role of parents and make it possible for parents to perform their role under law in support networks and individualized family support programs. This is a process of strengthening stakeholders for reducing the significant gap between the promise of the government in ratification and the genuine implementation of the UNCRPD.

As a result of joint efforts, leading parents began to organize together in mutual support and cohesive advocacy for environmental improvement and public education for their children’s rights. Parents get together in various forms from small, formal and informal groups to organizations. However, developing productive and effective models of parent advocacy for their children’s educational rights is not easy due to the challenges facing inclusive education as mentioned above and barriers confronting individual parents and their representative organizations. It involves, but is not limited to the following important issues:

The first issue is how to help parents change their perspective on disability and help them accept their children’s disability and value their lives. This is a real, severe, and widespread issue to be addressed. Many children with disabilities, especially those with intellectual and developmental disabilities, have been hidden at home by their families and lost opportunities to make friends, acquire adaptive social skills, or simply feel accepted. Many parents cannot come to terms with their children’s disabilities and feel fearful and shameful to expose them to others. On the other hand, when children face rejection and pity in public, parents normally adopt overprotection. In either case, parents do not receive adequate support for correcting their mistakes.

The second issue is how to support parents to understand and attend to the needs of their children. Children with disabilities might have different ways of communication, behavior, learning, and development. A shared vision of students’ learning by teachers and parents based on a cohesive set of goals is required to provide appropriate education to special needs learners. Therefore, understanding and attending to their needs are

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crucial for making and implementing plans for their development and best interest. Children spend most of their time with their families, especially during early childhood. Parents can help their children at the most critical developmental stage to reach to the fullest development possible if parents can attend to their children’s needs. Yet parents cannot fulfill this endeavor alone. They need a support system and network. The current situation is that, due to the lack of support, parents have to play so many different roles that teachers, specialists, and other professionals should have filled to help their children, or just give up when they feel helpless. The system can fail children with disabilities by not providing the support parents need to nurture them.

The third issue is how to empower parents to be active advocates for their children’s rights in challenging situations with persistent disability-related discrimination, prejudice, and rejection. Parents suffer from the negative experience of their disabled children. When suffering is consistent and prolonged it becomes a real problem for children, parents, and other family members, and impairs the whole family system. Parents and their children have to bear significant and destructive consequences. Empowering sad, hopeless, and pessimistic parents to speak up for their children can be challenging, but very crucial and urgent.

The fourth issue is how to help parents step out of their personal difficulties and contribute to collaborative pursuit of a better environment for everyone through peer support with other parents and contribution to strengthening the development of parent organizations. Parents are consumed by the hard work of taking care of a child with a disability. Yet, it is important to help parents lift their heads to see the bigger pictures of social and environmental disadvantages affecting their children’s sustainable well being, and realize that unless the environment is improved, children with disabilities will not have a fulfilling life.

The fifth issue is how to promote the professional and organizational development of parent groups so that parent support programs can be created and delivered to address the critical needs of parents. Meanwhile, there is a critical need for parents to understand the importance of parent organizations and to be supportive.

Given all of the obvious and explicit reasons to support, encourage, and empower parents for the rights of children with disabilities in inclusive education, introduction of good examples of parent advocacy through organizational efforts has significant and urgent importance. It is imperative to address who should be responsible for equal education of children with disabilities, why inclusive education is good for all children, what the fundamental principles of inclusive education and their practical implications are, and how to enhance parents’ involvement through legal protection for parents and government support for parent organizations to improve the quality of life for children with disabilities and their families. Introducing good examples can provide convincing evidence for addressing these issues and promote changes.
II. A GOOD EXAMPLE OF PARENT ADVOCACY

A. The Development of a Project

Guangzhou Yang Ai Special Children Parent Club is one of the leading parent organizations located in Guangzhou City that has evolved as a good example of parent advocacy for the rights of children with autism in China. It was established in 2003 by a group of parents with autistic children. In 2008, Yang Ai was involved as one of the three key players in a project supporting inclusive education. The purpose of the project is to explore practical and effective ways to improve the learning experience for children with disabilities in regular classrooms, promote policy reform on inclusive education at the local level, and change attitudes towards inclusive education. The other two groups were a social work department in a local vocational school and the special education center in the Guangzhou Youth Club. These three groups selected participating schools, prepared graduate students as paraprofessionals, trained special education assistants and introduced them into selected regular classrooms, recruited students with disabilities in selected schools and their families to receive support for learning, and worked with school staff and teachers to create a welcoming campus culture.

This project was launched at a critical period of legal reform on inclusive education in China when good examples of inclusive education became very important to promote the acceptance of inclusive education and relevant policy making. Beginning from 2010, the Ministry of Education began to draft the Regulations of Education for Persons with Disabilities because its predecessor enacted in 1994 was very outdated and became a barrier to the special education it was intended to serve. One of the core issues dealt with during the drafting process was to what extent this policy should emphasize inclusive education. The draft submitted to the State Council was released on February 25, 2013 to solicit public comment. A huge battle existed, which is still ongoing, between proponents and opponents of inclusive education. There were diverse groups on each side, including persons with disabilities and their families, experts, policy makers, school teachers and administrators both in general and special education. Even with good intentions, there was fear of inclusion due to misunderstanding or a lack of knowledge of inclusive education, and arguing that promoting inclusive education is unfair to students without disabilities. The most encouraging thing is that those who deeply understand the importance of inclusive education for all children with and without disabilities who will be contributing citizens for the country never give up.

In addition, the 1990 Law of the People’s Republic of China on the Protection of Disabled Persons was amended and enacted in 2008, a year after China signed the

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UNCRPD. A major improvement of this amendment is to prohibit discrimination on the basis of disability. However, in practice, children with disabilities have experienced exclusion in education and, most significantly, in inclusive education. The practice of placing children with mild hearing, visual, and intellectual disabilities in regular classrooms initiated in the late 1980’s has been problematic in the sense that included students only had a seat in a regular classroom. Even under certain relevant legal provisions, schools have been required to accept those who have the capacity to study independently in a regular classroom without additional support and services. The vague statement of the eligibility for inclusive education in relevant laws and policies, in fact, has generally offered leeway for regular schools not to accept students with disabilities.

Therefore, for decades, students with disabilities in general education normally have had negative learning experiences due to the lack of a support system, professional teacher training, parents’ involvement, and concrete and specific measures in relevant policies to regulate the practice. The shallow practice of placing children with disabilities in regular classrooms challenges the capacity and responsibility of the school system to offer education to children with disabilities if education means more than merely having a seat in the classroom. Furthermore, many children with other disabilities, such as physical disabilities, who need accessible learning settings and assistive tools and technology, autism, and other disabilities, have been excluded from general settings. There have been individual and scattered cases of general schools accepting students with disabilities other than the three typical disability categories protected by law. However, in recent years, several students with autism in different areas were sent home by their schools, either under the pressure from parents of students without disabilities or their teachers. Schools usually do not have preventive intervention for emotional and behavioral challenges and normally choose to get rid of students with special needs who might be disruptive. Again, in these situations, children’s special needs are viewed as the key problems rather than the lack of support services and programs to attend to the needs of each individual learner. The Chinese government began to improve educational laws and policies to address these challenges. But, pervasive misunderstanding of inclusive and special education, and rejection to inclusive education by local educational departments, school administrators, teachers, and parents of children without disabilities.

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A Good Example of Parent Advocacy for Rights in Inclusive Education in China

...have thwarted the progress. In the midst of prejudice and discriminations against the rights of children with disabilities in inclusive education, groups from civil society with the support of experts in the field have been exploring good examples of inclusive educational practice to promote legal reform and educate the public about inclusion education for all. The project under discussion was one of the cases of some successful efforts.

Before launching the project, a comprehensive strategic plan was produced to ensure a sustainable and evidence-based project. First, team leaders were organized together to conduct comparative research on inclusive education policies and practice, define the situations of inclusive education in the local area, identify needs for the development of inclusive education, and introduce special education assistant model. Secondly, Yang Ai collaborated with the involved social work department to provide training to senior students from this department at Yang Ai through internship opportunities, and to prepare these interns to be special education assistants for regular classrooms. Third, the Special Education Center of the Youth Club worked with the School of Education of South China Normal University to assist graduate students in this department to conduct research on inclusive education and serve as instructors to help design individualized educational plans, evaluate the performance of participating students at school, provide training to participating special education assistants and general education teachers, and nurture a welcoming and supportive school environment through various activities and events. Parents were invited to participate in the project in order for their children to receive assistance in regular classrooms.

Although most participating students had autism with additional disabilities, this project was to explore a support model that could benefit students with different disabilities. The participating students received individualized support from special education assistants selected and assigned by the project. Specific support included assessment of students’ level of knowledge, skills, and learning needs to make an individualized educational plan with the involvement of parents, support in the classroom for learning and engagement, strategic plans to address students’ emotional and behavioral issues, course design for resource rooms, strengthening peer support between students, and facilitating communication within the school for the overall understanding of the students.

About 30 students with disabilities were involved in the project and received support throughout the entire process of the project from 2008 to 2012. More than 30 special education assistants received training and contributed to assisting students. Increasing numbers of parents began to realize the importance of their involvement in their children’s education. Participating schools gradually changed their attitude towards inclusive education from questioning to welcoming. The overall culture in participating schools has been improved for inclusive education.
B. Parents’ Advocacy for Relevant Policy on Inclusive Education

In the process of exploring the effective ways to achieve meaningful learning experience for children with disabilities in inclusive education, leading parents began to think about how to use individual cases in the project to impact policy making, implementation, and raise awareness. In addition to the general value of parents’ role in advancing inclusive education, parent advocacy becomes very critical in China for the following reasons:

First of all, policy making in China is usually a top-down process with very limited participation of civil society, if any at all. This is the case for policy making on disability and causes the ineffectiveness of policies for failing to represent the interest of a targeted population. Second, parents are the earliest, closest, and longest caregivers and supporters of children with disabilities. Their role in protecting the rights of children, changing environment, promoting inclusion, and improving the quality of life of children and the family is unique and cannot be replaced. Third, families’ physical, emotional, and mental health needs have a significant and consistent impact on their children’s learning, attendance, behavior, and development. Therefore, parents’ needs should be conveyed to policy makers through advocacy and responses. Fourth, policy advancement through parent advocacy can benefit more children with disabilities that the policy targets in a large scale through community-based programs and policy improvement to foster successful family involvement practices. Fifth, effective advocacy of parents is an important channel to contributing to democratic participation in policy making in the whole of society.

In order to achieve productive policy advocacy, parent leaders made strategic plans and efforts, including: conducting comparative research on inclusive education through working with experts; collecting, analyzing and reporting data and facts; educating the public and working with the media; providing training to parents on how to present ideas and thoughts professionally and clearly and speaking up to the government; and representing the broader population and pursuing support from all stakeholders. The comparative research helped parents to focus investigation on the following issues: the status of inclusive education in the area; the professional support students with disabilities should receive in general schools; the number of inclusive schools and their practice of promoting peer support and nurturing mutual learning between students with and without disabilities; the ways to create a welcoming school environment; the number of schools willing to make curriculum adjustments for inclusion; the practice of schools that included the performance of students with disabilities into the school evaluation system, and the status of transitional education for children with disabilities after the 9 year compulsory education.

In addition to research, parents also collect experiences of disabled students as evidence. Parents used positive stories to enhance good practices and negative stories to reveal inadequacies and problems in policy and its implementation. Parents also held
roundtable discussions and workshops to share stories and analyze the key factors they indicated, and draft analysis for public education policy reform. As a result of parents’ active efforts, the media was involved in project events as a potent force to raise awareness, change perspectives, and eliminate discrimination. Many parents also had interviews with journalists from different newspapers and TV programs. Parents’ voices about inclusive education featured in the news to reach out to the general public. Social media functioned as a very effective platform for parents to invite people to come to the events held for children with intellectual disabilities and their families and interact with these children. In order to present their voices and suggestions in a professional way, parent organizations invited experts in the field, policy makers, lawyers, doctors, social workers, and trainer parents to form an advisory team for consultation and professional support. Yang Ai also formed a policy research team within the organization. Team members have received training on the UNCRPD through an international project for parent support.

Specific preparation and action included encouraging more parents to participate and acquire skills for effective and consistent advocacy, research and discussion on policy, training parents’ advocacy skills, and using an outcome-based approach. In 2009, leading parents in the project team began to have evidence-based advocacy for policy improvement to promote inclusive education, using the outcomes of the project. Different approaches have been taken to express parents’ thoughts, concerns, and ideas through meetings with policy makers, sending letters to relevant departments in the government, and submitting proposals to the annual sessions of people’s congresses and the Chinese People’s Political Consultative Conference held both at provincial and city levels. Parents were assigned to different groups according to their strengths to work on different issues they wanted to address with the government and to schedule appropriate meetings with policy makers accordingly. They took with them information and useful materials pertinent to critical issues in inclusive education and proposals of suggestions and recommendations to facilitate the meeting and keep policy makers informed and oriented. To make their voices strong, consistent, and coherent, the parent group leaders designed and conducted surveys to collect opinions broadly from many parents. One of the key issues they addressed most was to ask inclusive schools to establish resource rooms and recruit special education teachers to improve the quality of special education for students with disabilities through professional support for learning. They also worked with media to reveal challenging issues of inclusive education and introduce the project’s progress to draw attention from the public to inclusive education.

In addition to strategies, parent group leaders also have a general principle to guide their advocacy: good understanding of the needs of children with disabilities and their parents, and scientific methodology. This principle helped parents to continue to gain the knowledge and skills required, master effective communication, develop positive relationships and network, and persist and persevere.
Parents’ efforts were very fruitful. In April 2012, the provincial education department released a policy, “Provisional Policy on the Establishment and Management of Resource Rooms for Children and Youths with Special Needs in Inclusive Placement.” The policy required that there should be at least one inclusive school in 3–5 schools in each district. The school should establish resource rooms, assign teachers to them, and provide an individualized educational plan for each student with disabilities.15 Government officials also consulted closely with parents to discuss solutions and listen to parents’ ideas and concerns. In February 2013, The Guangzhou government enacted a policy “Suggestions on Strengthening Implementation of the Work on Special Education in Guangzhou City 2012–2016,”16 which officially included special education into the five-year work plan of the city. The highlights of this policy include the following:

1. Improve special education and expand compulsory education to students with disabilities to 9 years plus 3 years transitional education;

2. Develop special education system to provide professional guidance to inclusive education, establish an instructional organization for education of children with visual impairments, hearing impairments, autism, and intellectual disabilities;

3. Administer and establish base schools for inclusive education. Three to five schools in the same region should work as a group and one of them should be a base inclusive school. Special staff and funding should be provided to base schools to serve their purpose. Resource rooms should be built in base schools according to the standards delineated by the provincial and city policies;

4. For special education training, general education teachers should receive training for at least 12 classes, and special education teachers 24 classes. Teachers get an additional 30% of their salary for special education related work they are involved in;

5. Implement an individualized education plan system; special education teachers are required to provide instruction to inclusive education and there should be a system to ensure regular instruction;

6. Provide additional financial support for students with disabilities to learn in inclusive schools; the amount of funding should be less than five times the funding regular students receive;

7. Before 2014, educational bureaus at different levels should finish training all parents of students with disabilities. Parents should receive training at least twice a year.

These policies contain comparatively specific provisions for inclusive education that

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other parts of China should learn from. It would be unlikely to see such local policy advancement in the area without the well-planned, organized, and strategic efforts of parents. Parents and their representative organizations in other parts of China have been learning from Yang Ai through collaborative activities and events for the purpose of pursuing policy change in their respective areas. The progress in policy reform at local and provincial levels will have positive impact on national policy and law making, such as the draft of Regulations on Education for Persons with Disabilities mentioned under revision for approval of the State Council. Apparently, closing the gap between the law and its implementation is a challenging endeavor. A strong support network for parents and their representative organizations will be crucial to this pursuit. All advocates for inclusive education hope that international and domestic efforts can help make inclusive education the core of educational laws and policies. The government is planning to produce the country’s first law on early childhood education. Whether early intervention and supported early childhood education for children with disabilities become an integrated part of this law will make a difference to inclusive education practice from school age and beyond. There is a long way to go to change a broken legal system for all children with different learning needs and gifts to one with a rich learning experience and individualized education in their best interests. It requires a vision for a multifunctional school system and community with many paths toward sustainable success.

CONCLUSION

There is no doubt that the presented case is a very rare and unique, yet deliberate, meaningful, and important one in China, the context of which many groups, especially parent groups, want to follow and learn from. In general, it opens a window for policy makers, school system, academics, and parents to think deeply about the critical role of parents in students’ success and consider what is missing in supporting children with disabilities and their parents for the development of inclusive education. It revealed the fact that students with disabilities will continue to experience exclusion and failure in their education and beyond if evidence-based solutions introduced by these parents and their supporters are ignored or undermined. Consequently, their failure will affect, on the daily basis and in the long run, the quality of life of each member in the family. Students without disabilities also miss an opportunity to develop a deeper and broader view of what success means beyond academic performance. This case is typically important for parents and their organizations and other supporters from civil society to learn from in order to duplicate and create more environmentally appropriate projects and begin to take serious and immediate action. The following are some suggestions and recommendations:

(1) Experts in the field, parent organizations, and policy makers should think about the definition of family involvement and make it a critical point for legal reform if the country is to implement inclusive education that helps all students succeed, have a broader view of what success and life is, and learn from diversity and life values. The
definition should embrace the role of parents and families in advocating for educational opportunity and equality.

(2) To achieve successful advocacy and positive impact, parents need to be cohesive, consistent, cooperative, informative, and organized. From a group perspective, random acts of family participation lacking a systematic approach can be weak, impaired, confusing, contradicting, and consuming. Parent leaders and their representative organizations need to promote a research and project based plan and a coherent and comprehensive strategy for parent advocacy. From a broader social perspective, it is the process of educating the public to understand the important issue of parents’ role that has been neglected for so long. Well-equipped and organized action can, in turn, increase the return of parents’ efforts and ignite sustainable progress through joint efforts. To be able to educate the general public, parents should educate themselves first.

(3) Parents should realize that their children with disabilities could not go far and have a fulfilling, decent, and independent life if the environment is not welcoming and inclusive. Mainly fixing their eyes on temporary relief and solutions within the family will not be helpful for sustainable opportunity and improvement of their children’s future. Parents should work with other parents and their representative organizations to educate the public for the advancement of their children’s rights in education. Parents’ support to their children can be more effective when parents share wisdom and strength with each other and empower each other to change the community and society.

(4) Parents should create strategies and networks to work with other groups. This is a very simple but important point. Parents have their unique role other groups cannot replace. Successful parent advocacy requires professional support from other groups. Parent groups should pursue a support network for effective involvement. This is critical in an environment in which parents’ role is undermined and unattended. A strong network for parents will be helpful for strong parent advocacy both in its preparation and action. To become supportive of parents’ role is also a process of educating others.

(5) Last but not least, to improve the lives of disabled children and their families, it is imperative to be aware of what is counterintuitive in the laws and policies due to the absence of necessary provisions for parents’ rights and responsibilities. Governments at national and local levels should realize that parents and their organizations are helping the governments in improving the educational opportunities and outcomes of children with disabilities. Families are systems. Whatever happens to one member of a family affects the whole family and each member in the family. Governments should provide policy and funding support to parent organizations to duplicate the good examples and create more effective projects. It is the government’s obligation to protect and empower parents for their children who are future contributors to the country.