



Olivia's at four

Since opening in 2010 Olivia's Place has grown to become one of the leaders in the provision and advancement of special needs education, not just in Shanghai but China. **Douglas Parkes** speaks to cofounder Nelson Chow about raising a daughter with Down's Syndrome and pushing reform in China

Why was Olivia's Place established?

Olivia is my daughter. She's six-years-old and she was born with Down's Syndrome in Shanghai. That was when my wife and I were first introduced to care for special needs children in China. When she was born, the nurses completely freaked. My wife had just undergone 20 hours of labour and a C-section. After the operation the nurses quickly pulled me over and said, 'Don't tell your wife, don't tell your wife!' As in, the news might devastate her so much she'll never recover.

So Olivia's condition was obvious from the start?

It's obvious from day one. Down's is one of those conditions you can diagnose instantly. There are certain signs – the shape of their eyes, the length of their ear lobes – you can do simple tests and know with 90 percent certainty. It took a few months to confirm, because genetic testing in China takes time as

they have to send everything away, but when we got the results, we knew we had to act and do something.

What was your initial reaction?

Personally it was very challenging. Olivia was our first child and you have all these hopes: that she can graduate from college one day or get married some day... And you recognise very quickly that this may not happen. A Down's Syndrome child's life span is short, it's probably 40 or 50 years. It's getting longer now, but a parent could easily outlive their child. You start thinking about all these things and it bothers you. It's very easy to get into that dark place and you have to pull yourself out of it.

But after coming to grips with things, which took a little time, we realised we needed to help

Olivia with whatever we can and that started our search for therapy.

How much did you know about special needs at that stage?

At the beginning, we didn't know what to expect. We didn't know the accepted standards. We searched for a whole year and kept thinking 'This can't be right, can it? Is this all the support that a Down's Syndrome child can get?'

My wife posted on Shanghai Mamas and Maggie Tuk Tucker, one of our cofounders, a very knowledgeable occupational therapist, responded to her post

immediately, saying 'You've got to get your daughter to a therapist as soon as possible.' That's the whole concept of early intervention: to help the child as much as possible as early as possible, since that makes a bigger impact.

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What help did you find during your initial search?

We looked at the foreign hospitals and among the local ones and at each we saw a lot we didn't like. Among the foreign ones there was no multi-disciplinary clinic and quality was very spotty. No one had assessments; doctors were just eyeballing Olivia and telling us, 'Oh, your child *seems* able to do this.' Cleanliness was a problem too: rooms optimised for therapy didn't exist. I remember going to one of the expat hospitals and being seen in a dental office. There was an overhead drill hanging down, plates of sharp tools everywhere and Olivia was crawling around and coming up with filthy black hands! And we saw the whole local situation, too, which was basically non-existent.

That sounds awful. What happens to local individuals who have special needs then?

For adults, what happens is they end up being released. There is no rehab. Among children they're basically institutionalised; put in an attic and abandoned. That's why they end up in orphanages. Parents feel there's no hope – as we experienced when the nurses reacted after Olivia's birth. We realised this is not what we needed for Olivia and moved back to the US in 2009, when she was almost two.

So why return to China?

My company was very keen for me to return to China and after nine months in the US we had a better idea of the situation. We knew there were therapists in China, trailing spouses, who couldn't get work here because there were no clinics and thus no jobs. So we thought, why not try them? We could be the case manager and we thought we'd be able to do that for a few years because we knew a bit.

That's what we thought we were coming back to! When we returned, things were very different. All the therapists we had known were gone and for a month and a half, Olivia had no therapy and we were beating ourselves up wondering if we'd done the wrong thing and agonising over whether we should have returned or stayed in the US.

At that stage my wife and I sat down and said, 'If Olivia's not getting the help she needs maybe we need to do something.' And we decided, if we open a clinic, it's got to be about more than Olivia and the expat population. The expat population has a choice; after all, they could go back to their home country. It's got to be about the locals, because these people are abandoning their children. We need to bring in foreign talent and we have to use their knowledge and spread it about. So that became our mission: to bring about and develop Western-style therapy in China.

Was setting up Olivia's Place in China an easy task?

Doing business in China has its challenges and is different from the US. I have been fortunate enough in America to have opened businesses, so therefore I had experience starting up companies, though it's totally different here.

Fortunately we're in an area that the Chinese government really wants to develop, so they've really embraced us and drawn us into the inner circle of their rehab reforms. At the start, when we first asked for meetings they were all, 'Who are you?' Early on we used the [Olivia's Place] Foundation funds to drive a lot of community-based work and I think through that they saw we were willing to do a lot of work without looking for anything in return. That broke down a lot of barriers. They

recognised we were here

for the good of children, that we weren't going to use helping children as cover for some other mission or look for compensation.

Have you noticed improvements in Chinese services since the government came onboard?

Yes, it's a complete change from four years ago. A lot of that is coming from increased awareness. Hospitals are encouraging staff to separate occupational therapy, physical therapy and speech therapy, and to give one-on-one therapy.

What about schools? Are they equipped for special needs children?

They're not really equipped for this sort of support. There's no support for inclusive education within the school environment. International schools understand the need for this and are more willing to take on special needs children now. Four years ago, they were more selective and not really interested in taking on such children and providing the necessary support. Now they're making much more effort and investing more. Among the local schools it's very different. The community is still completely segregated; there's no inclusive education. One thing that *has* changed is that while before local special needs kids were institutionalised in a caretaker facility, now these institutions have morphed into special needs schools providing education. It's not in an inclusive setting but, still, we have change there.

You mentioned Olivia's Foundation earlier, what is that?

It's US 501(c) approved, which means it has nonprofit status. We use the Foundation to help subsidise therapy for those who otherwise couldn't afford it, regardless of nationality. It's for causes throughout China and helps with things like sending a therapist out to an orphanage. It covers education, too, not just therapy. We raise money into the Foundation and we have a review board made up of doctors, international hospitals, etc, and they're the ones who determine who gets what.

How did the foundation get started?

It began the same time we founded Olivia's Place. We wanted to bring about therapy change. We realised not many of the local population could afford what we do, so we started the foundation. That tapped into my, my wife and Maggie

Tai's vision of giving back to the community. We see it as an interim solution until locals can afford proper therapy and understand what it is. They can rely on the Foundation until then.

Olivia's Place is a permanent fixture here in China then?

We plan on being here until we accomplish our mission. A lot of people say to me: 'Nelson, your mission means you might drive yourself out of business in 20 years,' because if you think about it, if we bring therapy to all of China, we're not really necessary any more. And I respond, 'If that actually happens, I'll be happy.' We'd have accomplished our mission. All of us at Olivia's Place can go back to our home countries and say we were the ones who affected that change for kids. It's so hard to accomplish something that meaningful in your life. If in the future every city has hundreds of clinics offering therapy, I'll be very happy because it'll mean we've succeeded. That's the end point. When we're no longer needed, that'll be great.

Olivia's Place 35 Yongjia Lu, near Maoming Lu, Jingan district (5404 4055; www.oliviasplace.org). ©Jingan Temple. 静安区永嘉路35号, 近茂名路



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