



I couldn't understand why people would give money for offices and not for a youth space.

Sonia Thursby

Sonia learnt how to be an advocate for social justice and social change from an early age, because she spent a lot of time chasing kids at school who bullied her best friend who had a disability. *That was my first social justice act: To say it isn't okay. We're friends, so you need to treat us the same.*

Sonia and Kaz have known each other since they were two years old. They grew up in London, lived in the same neighbourhood and started school together. Kaz was born with both her feet turned inward and was unable to walk. As wheelchairs were costly and hard to come by, Sonia pushed Kaz to school each day in a child's pushchair. *During that time young people could be really mean and call her names. It was awful! So I used to spend a lot of time putting the brake on the pushchair; running and chasing people to stop them being so mean.*

When Sonia and Kaz were both 13, they joined a youth group called PHAB (Physically Handicapped and Able Bodied) which was part of the Youth Services branch of the Ministry of Education in the United Kingdom (UK). This was a place where young people could come together, support each other, socialise and de-stigmatise disability. The vision statement for PHAB was 'Integration—making life together'.

Sonia was always enthusiastic about exploring extra-curricular activities. She loved getting involved in organising community events, youth events and school activities. *My parents just got used to me always doing something and enabled me to volunteer for things.* Sonia saw PHAB as an opportunity to be part of something big, something that addressed injustice and inequality in society. By the time she was 16, she was running a local PHAB group, and then joined the PHAB National Council as a local representative. In the 1970s and '80s there were 58 branches of PHAB in the UK; today there are over 500.

Once she left school, she continued to volunteer with PHAB while training to be a youth worker. After she married and had children, Sonia re-trained as a preschool teacher. It was during this period, living in Bournemouth in the late 1980s, that she read a discussion document published by the Ministry for Education entitled *Youth into the '90s*. To her amazement there was no



mention of youth services for, or of the educational needs of, young people with disabilities. Sonia lobbied the Ministry to be more inclusive of youth with disabilities. Eventually she was asked to write a chapter for the document on this area of need. But it didn't stop there. She was also invited to develop a training programme and tour the UK to train youth workers working with disabled youth. She loved the experience and realised that she wanted to return to youth work and, in particular, to working as an advocate for youth with disabilities.

Sonia emigrated to New Zealand in 1993. The scene in New Zealand was very different from the UK. New Zealand was only just recognising the need to de-institutionalise people with disabilities, mental health and aged care needs, and home-care services were only just beginning to be provided. There was no official training for youth workers. Sonia could not find any organisation supporting youth with disabilities, so she returned to preschool teaching.

One day she saw a job vacancy in the *Herald* for someone to establish five 'disabled clubs'. *I was like, That's my job!* At this time most of the services for people with disabilities were provided by church-based social service agencies. To her horror, Sonia discovered that the youth were looked after by aged care services and did not mix with people their own age. *It was just soup and crafts each day.*

Sonia got the job and was employed for 20 hours a week, during school terms only. The agency that employed her had a contract with the Ministry of Health. Sonia was expected to establish five clubs for youth, each with their own management committee, within one year. She was determined to meet this challenge, but found it an impossible task to do in the 20 hours allocated, so she took on the job full-time for a year, whilst only being paid for her part-time hours. She succeeded and clubs were established in Te Atatu, Mt Roskill, two in South Auckland, and one in a church hall on Lake Road, Takapuna. However, Sonia was still dissatisfied

*Sonia 18 years old, on a PHAB camp,
—a day with riding for the disabled*

that youth with disabilities were on the fringes of society, and were not socialising with able-bodied youth their own age. She was also unhappy that there was no actual service to facilitate support services and activities for youth with disabilities.

At this time Sonia met two key women who were to be of great support: Joyce Lavender and Joan Lardner-Rivlin, who had set up PHAB in the 1970s, running summer holiday camps for able-bodied youth and those with disabilities. Joan had brought the PHAB model to New Zealand from Hong Kong, where she had been a youth worker and PHAB coordinator. The camps were no longer running, but the two women still had a small office in Northcote and a bank balance of \$1000 for any future PHAB activities.

Sonia lobbied the Ministry of Health, arguing that PHAB was the ideal organisation to provide a wrap-around service for youth with disabilities. *I just went to the Ministry of Health and said you cannot keep these young people with the older people—it's just not working—and I've found this organisation (PHAB). So they agreed and that's what we did.* She invited members of the clubs she had established to be the PHAB management committee.

The first year that Sonia re-established PHAB in New Zealand was also the 25th anniversary of PHAB in Hong Kong, so she organised 14 young people with disabilities to travel to Hong Kong and join in the celebrations. Organising the logistics for the trip was a challenge, as eight people were in wheelchairs but, for all who went, the trip was a huge success. Sonia took everyone over the border to China on a day trip to see pandas in a zoo. She recalled that the crowd that had gathered supposedly to view the pandas were instead watching them in amazement, as disability was still invisible in mainland China. From that day on the group coined the phrase, *We are a social success!*

Back home, the young people were still meeting in church halls across Auckland. Sonia wanted to focus on what she might be able to achieve on the North Shore and to find a venue where youth



Sonia making posters for a PHAB carnival, in Christchurch, Dorset, England, 1985

could meet and make their own, a space that would belong to PHAB members. It happened that the Takapuna women's bowling club in Auburn Street was up for lease. It was a good-sized venue and Sonia remembers thinking, *'Oh my God, I can turn this into the most amazing youth centre.'*

She put in an expression of interest to North Shore City Council, which was accepted, and she got the lease. PHAB was given permission to refurbish the space. Sonia approached the young people and asked them to draw what features they most wanted to have to make it their space. *They drew a picture and I gave it to Logan Brewer [a local architect] and I said, Can you please design this?*

In 2004, the refurbishment was complete. But what would the new place be called? During the work, every time anyone mentioned the space it was always referred to as *'the building'*. Sonia canvassed PHAB members about a name for the centre and everyone agreed that it was already known as *'The Building'*, and so it remains today. The name also became a slogan for PHAB: *'Building me, building*



you and building us. By now Sonia had one paid office worker and several paid part-time youth workers.

The next turning point in her career came with the creation of YES Disability in 2006. Its main office is in Albany. YES was to be a *'one-stop shop'* for all people with disabilities. Sonia was very critical of YES in its early days, arguing that there was no need for such a huge office building and that it was too far away geographically. The local Rotary club was the primary sponsor of the new venture. *I couldn't understand why people would give money for offices and not for a youth space.*

Sonia attended every YES network meeting and voiced her concerns. She felt that YES was not doing enough for families of young people with disabilities.

Long story short—I'd go to each AGM and say, What are you doing? This continued until she was asked in 2010 if she would take on the role as chief executive of the service. Sonia hesitated until someone said to her that she'd been critical all this time; now she could have a chance to turn it around and make things work. Sonia went on the board, initially for two months, and then accepted the role of chief executive for one year. She felt a huge obligation to deliver on her concerns. She also saw this as an opportunity to be in a position where she might influence change at a policy level, as YES had the capacity to lobby for change across the sector. *It was bigger, shinier, and massive! It wasn't just a smaller organisation delivering services at the grassroots.*

The office space in Albany is now shared with Taikura Trust, which provides disability needs assessment services, as well as Youthline and Carabiner, a mentoring programme for youth with disability. Amongst its many core services, YES also provides a leadership programme for youth, and a youth-run anti-bullying campaign and support programme. In 2012, YES was instrumental in developing the CUBE, a collective impact model involving 11 organisations working within the disability sector in Auckland. The aim of the initiative is to give young people the opportunity

to govern, take leadership roles, and design programmes for themselves, by themselves. *Young people with disabilities want to be young people first. This is also the first time that young people with a disability have had decision-making power for themselves. They've always had either their parents or a caregiver make decisions for them. This is an opportunity now for young people to lead from within the CUBE.* There is now interest in taking the CUBE model to Christchurch and Hamilton.

Sonia gradually reduced her hours at PHAB and today works there on a voluntary basis. She is still with YES Disability and has worked hard to address the service delivery needs of families caring for someone with a disability and for youth aged 16 to 24. Sonia's goal has always been to work herself out of a job. She dreams of a day when there won't be a need for services just for youth with disabilities, when all youth services will be integrated.

If you had told me years ago that I'd get to my age and it wouldn't have happened—I'd have laughed.

