Chapter 1 – Lifetime Advocacy

Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy.
Proverbs 31:8-9

As parents to a child with a disability, our life changed the moment we became aware of their disability, they were born or were diagnosed with the disability. We struggled to gain proper schooling, proper health care, proper access to amenities, even an accurate diagnosis, throughout their childhood. As our children grew up to become adults and we, as parents, grew older too becoming too frail or friends our age dying even, the need to ensure continuity of care became ever more pressing.

Who would ensure our children had the care they needed after we're gone?

Who would visit them and show a real interest in what they are doing?

Who would make sure they are dressed appropriately and not put in clothes belonging to others.?

Who would take them out to a restaurant or cinema and allow them 'access to the community'?

Who would support them if they needed to move accommodation?

Who would argue their case with the authorities to get an appropriate package of care?

You might think these are not real issues, but trust me, they are, and they have happened to our children. Our advocates have supported our children in these very situations; and that is whilst we are still alive. It would have been even more crucial had parents passed on and the advocates had to act on behalf of our children.

Our daughter Chrissie and our family have been with Kith & Kids since she was 5yrs and she has benefitted enormously from the 2:1 Social Training Projects held during the Spring, Summer & Christmas holidays. What we would have done without this outlet? God only knows. She had 2 volunteers with her during her developing years ensuring she could reach her potential in art, music and drama. We could see her confidence growing each year. She did love to run around and just observe. She has always liked observing others rather than taking part. Disney holidays with the family were similar, we'd queue for hours and then she didn't go on the ride. Happy to just watch.

“By sharing your problems with your friends, you can cut them in half.” Anonymous

Meet with other parents

Joining Kith & Kids was one of the best decisions we made as a family. We met other families who were experiencing similar issues with their disabled child and others who had already been through the stages we were then facing. We met every Tuesday at one of the parents’ houses and took it in turns to speak about our situation. Looking back, it seems a bit like an AA meeting. “Hello, my name is Peter, and I am Chrissie’s dad…” I used to joke that if you could not make a Tuesday evening you couldn’t be a member of kith & kids.

We also met every other Sunday at Corum’s Field near Russell Square; this time in the open air, having fun with our children and volunteers. If there were enough volunteers some parents were able to get away and enjoy a coffee together. If not, we clubbed together and, sometimes with our children, made a picnic together. I recall making fruit salad with others with more fruit eaten before it hit the bowl. It was fun, we chatted, we understood.

Our children were young then, but they very quickly soon get older. The issues we encountered was getting the local authority to acknowledge our child’s disability in a formal way and to get them “Statemented”. This would then get them officially recognised as “disabled/autistic/learning whatever”, which is fundamental to getting the correct support and/or a funding package of care for them.

Getting the right school for them is the next stage and after school years have finished, where do they live? Do they live at home with us forever? Do we look for a residential home for them? What is Supported living and how does it differ from residential home?

Meeting with other parents and listening to their advice was a life saver and it was the key to the success of Kith & Kids. These meetings gradually resulted in a group of parents all being worried about what would happen to their children after the death of the care givers putting the early stages of an advocacy project in place.

“I want my child to be happy”, said a parent. “No, you don’t” I replied, “You want them to be fulfilled”

What does a parent want for their child? I had a conversation with a friend and asked him what he wanted for his son in the future. He replied “happiness”, which I thought, again, was possibly unmeasurable, but I thought about it and said, “no you don’t”: usually a response that gets the hackles up. But I continued, “what you want for your son is that he is fulfilled in his life”. In other words that his son achieves what his son wants to achieve and is comfortable with that and he has self-worth. The same is true of parents who have a disabled child in the family, they want the child to be fulfilled, to have a sense of worth in their life. Our daughter now lives in a supported living arrangement, renting a first-floor maisonette in which she has care staff 24/7. We felt that she needed an activity other than TV, music and walks to the park or shops. We knew from Kith & Kids projects that she liked craft work, so we arranged for a lovely lady, Zoe White, to teach her staff how to support Chrissie with these activities. To our delight the staff really got involved and now Chrissie is supported to produce the most amazing things, and these are posted on our family WhatsApp every day. The smile she gives when displaying her latest artwork is a real pleasure. To know she is creating and enjoying the creation demonstrates to us real fulfilment.

Life is not always plain sailing, there was a dreadful situation, which showed our need for the Kith & Kids advocate to be even more necessary. Due to her obsessiveness in her diet and the type of painkillers she was prescribed for early onset arthritis, she got severely constipated. This brought on a psychotic attack. She was hallucinating, terrified and running in all directions for no apparent reason. Her time in the hospital was nerve racking and the medics even contemplated installing her into a 'mental institution' *(I didn't think these even existed anymore).* Fortunately, they eventually realised the cause and prescribed Movicol, which assists one's bodily movements *(helps them shit, to put it bluntly)*. This time was not pleasant for her care staff as she was running to the toilet about 8 times a day for about a week and sometimes she was too late. It took over 3 years for her to overcome the incontinence. It took a further year for the other effects of the psychotic attack to fade, during this time we needed to apply for further funding from social services towards 2:1 Care in the community. She was a danger to herself *(by running away without warning, and she is a strong girl)* and others *(she was freaked out by children and dogs and could lash out at babies or get hurt by a dog)*.

"Advocacy is empathy, compassion and community at work."**- Janna Cachola**

We held several meetings with the Council and although we spoke eloquently, we were not getting anywhere. It was only when our advocate spoke up, did they begin to register Chrissie's need. They agreed to fund her for an extra staff member for up to 16 hours per week. Result! This made a huge difference to her life, being able to go out safely and enjoy walks in the park or places away from people. It took a long time before it was considered safe to even venture into Costa coffee shops.

The original concept was to have advocates/friends who could speak out for our disabled children in the event of our passing. However, life is not always as linear as this.

Unfortunately, many of our 'children' have died before their parents.

May they rest in peace.

Stephen Dawson
Neil O'Brien
Kim Collins
Wendy Liebert
Jemima Brook

I am told there is nothing as gut wrenchingly painful as losing your child. Our advocates are now being trained and tasked with being proactive in supporting these parents.

Because of these scenarios, klasp was born. KLASP: Kith & Kids Lifetime Advocacy Support Project.

How did we go about setting up our group?

Naming it was fun. Trying to find an acronym that meant something and didn't sound bad. We had many a meeting where we shared ideas, one of which almost became KLAP. Kith & Kids Lifetime Advocacy Project – but we didn't feel we should give ourselves a round of applause, and it also sounded like something unpleasant.

"Hello, we're raising money for the klap" ☺.

Also, we felt that the project was one offering "support" to both the parents now and to our children now and in the future. We have found that many of the care homes and supported living accommodations also benefit from the 'support' we offer. So, everyone wins, KLASP it was.

Our original branding was in the Kith & Kids blue colour with a close-up picture of an adult hand 'clasping hold' of a child; fitting we thought.

Our branding is now orange and incorporates a strapline of:
"A voice for adults with autism or learning disabilities who cannot speak for themselves."

"Why orange?", I hear you ask. See the following chapter "Key to unlocking potential"

Thinking of forming your own group?

Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible. **Francis of Assisi**

You will need to get together with other parents in a similar situation and align yourself with a local charity or form your own charity. You will also need to consider the long-term management as well as the short term. Considering the purpose of our project is to ensure our children are cared for when we die, it will inevitably need siblings or others to eventually take over the running of the project. Most importantly, if it is important to you and may well be important to others, so do not give up on your dream. It may take several years to get your ideas together and then to get your finance in place, but keep going and keep supporting each other.

Nothing in this world can take the place of persistence. Talent will not: nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not: the world is full of educated derelicts. Persistence and determination alone are omnipotent. **Calvin Coolidge**

A management committee will need to be formed with a small group of you to take on the responsibility of setting out the goals and ensuring there are sufficient funds to maintain and improve the service. The make-up of our group is very mixed, we have Maish Collins; a businessman of long standing, full of ideas, <u>determination</u>, and an ability to inspire others. We had our current Chair, Hilary, who is perfect with protocol and keeps us grounded if our ideas get too esoteric. Tilly, Angela, Lisa who are siblings and who are up with all the latest technology and communications ideas, other parents, Linda Dawson & Lesley Brooke who bring common sense to our many long discussions. Then there is myself, & Ralph Rosen fired with enthusiasm & <u>persistence</u> and who set up the first shop and who often like taking holidays while leaving the other to cope! Ralph had to take a step back after his beloved wife Sandra passed away and he felt called to support another with a disability. Shows what a caring man he is. At the start of our journey, his commitment and dedication was a fire under my engine. He is still a member of the committee.

At the time of writing we have now taken the bold step of transferring the management of the project to the trustees of the kith & Kids charity. The project is now fully operational and acting under “business as usual”. It is only right that the trustees have the oversite of all the projects we run and not just some of them. At our start, for whatever reason, the trustees were not willing to fund or support this need as they did not have the resources available. Now the scene is different, and it makes sense to fold the “start up committee”. As it happens many of the initial committee are now also trustees, so the project will always have its supporters.

Taking risks doesn't mean shirking responsibility, but embracing possibilities.

Vic Hope

There is always a balance between diligence and dynamism.
You can have £10,000 in the bank and be willing to take the plunge and employ your first advocate and you can have £100,000 in the bank and be cautious in employing the next. We’ve experienced both.

With an ‘advocacy project’ the main expenses will be paying the staff, National Insurance and Pensions, training of the staff, and paying their expenses: travel, office equipment and maybe meals out. Whatever money you have, you will need to ensure you have a constant flow of it going forward, otherwise you could set up and close within a very short period. Don’t forget to have a redundancy fund put aside. Where resources allow, more working days may be added to the staff contract and/or more frequent visits may be offered to the children. To ensure that the group can continue after the death of a parent they should make a provision within their Last Will & Testament. This can be in the form of a lump sum gift or by a lump sum and/or continuing contribution from a Discretionary Trust that is set up for the child either before death or on death via the Will *(seek legal advice about your own situation, as trusts are not cheap to set up or run).*

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." ― **Margaret Mead**

Our project started when we had 28 families and 30 children alive who needing monitoring. We wanted to start with fewer families so that each got more hours from the advocate, but it became too popular. We even started a second klasp group within the charity and they had their own management team and fundraising efforts. But that is another story! Since Covid hit, we have decided to merge the two groups anyway. We lost several our children, during the pandemic and, to their credit, the parents still maintain their involvement in both time and money. They realized that the service is still important to all the children in the project not just their own.

If other children do not join then, ultimately, the KLASP group will reduce until there are only a few members being looked after and this would not a sensible use of resources, thus the more practical aim would be to maintain the case load of each staff member to a full 5 days a week level, or whatever hours your advocates wish to work. As one child/family leaves KLASP then another can be brought in, which is why we merged our two advocacy groups into one.

If you are interested in forming a group or know of a group of families who are struggling, please feel free to reach out *(see contact details at the back of this book).* We're happy to help guide you or them through the process and set the group on the right path. Each group is different and will have differing needs. The same is true of the parents within our group.

We have a few families where their child is still living at home with them. This brings its own challenges in terms of respite, but also when it comes to the parent passing. The shock of losing a parent when you are a child with a disability is compounded by the practical issues involved. If you have suffered the death of a loved one, it is painful, but at least you are in your own home with familiar things around you. Imagine having to move home at the same time. Compound this with having strangers moving your possessions into boxes and not knowing where your things are, no mum or dad to ask or cuddle. Then being moved into a different home that is unfamiliar with a new set of strangers. Perhaps this new place being a bit smaller; instead of your things being across the whole of your house, these strangers having to reduce your possessions to fit into one tiny bedroom as you are now in a group residential setting. All this happening with no family around you. I would say this is unimaginable pain. If at all possible, this move should happen way before the parents have died. The move will be upsetting enough, but at least the parent will be there to support.

Other parents have their child in either 'Residential living' or 'supported living' settings. Some of these have transferred from residential to supported living within the same housing. Some of our parents do not wish to have a week-by-week involvement with the advocates, but only when the 'need' arises. Others want the advocates to, in essence, be their friend. To be fair, all parents would want the 'advocates' to be a friend to their 'special needs' children. How else can a relationship be formed in order to be able to understand how the child thinks, feels or behaves?

"From caring comes courage." — **Leo Buscaglia**

Many parents value the support offered by the advocates when they are in meetings with Social Services, the Care provider or even at the doctors. I remember a meeting we had with a psychiatrist for our daughter; we met to discuss and review her medication regime. At the meeting there was myself and my wife, my daughter and her two care workers, her klasp advocate and a member of the Care provider management. Seven of us in a meeting with the medical professional; not really overkill!!! There was a funny moment in the meeting as I was describing how, when Chrissie gets upset by a noise or a jumpy dog, that she would scream very loudly "GO AWAY", and how I was able to distract her by saying "squirrel". As I said this I pointed out the window of the room we were in, and everyone looked out the window. The place fell about laughing.

As parents we may have an idea of what is best for our child and what they need, and we may even be articulate enough to express this. Parents have no legal say in their 'Adult' child's welfare. If an 'Advocate' says the same things, they get listened to and often those same points get acted upon. An advocate may even have their own views on what our child needs, sometimes better than us oldies!

Don't be put off because the family's needs are so diverse, embrace it. There will come a time when one family is in dire need of much support, it is at these times that the group will need to be flexible and realise that the other families may need to accept a reduced service until that issue is resolved.

I hope our story is an inspiration to others who may be thinking of taking that next step.

Our next chapter goes into more detail into one of the ways you can generate long-term consistent funding, but it is by no means the only way.