

## Love is simply not enough

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### Abstract

**Purpose** – This article aims to tell the story of the author's son, Joe, and how, as a family, they have sought safety and security for him and themselves.

**Design/methodology/approach** – The article draws on the author's own experiences and those of other families.

**Findings** – A secure future for Joe (and other adults with a learning disability) depends upon families working together and ensuring good networks of people who care about what happens.

**Originality/value** – The experiences of individuals and their families are central to an understanding of how to ensure a good life now and in the future.

**Keywords** Learning disabilities, Family, Circles of support, Future planning

**Paper type** Case study

I do not love him because he is good, but because he is my child – Rabindranath Tagore.

On the 11 April 1989 I was sat in an isolation ward in Wigan Infirmary being told my six-month-old son Joe had a very serious case of meningococcal meningitis and would be lucky to survive the night. We were told if he did survive he could be left deaf, brain damaged or with other serious complications. The thought inside my head was simply "it doesn't matter", I wanted my baby to survive, whatever the cost. I knew that I loved my child so, so much that even though he had been hurt once by this terrible disease, I would never let him be hurt again. My reaction was to hold my child, to nurture, protect and love him forever. But would love be enough to see him through his life?

The reality of life soon kicked in. We were discharged from hospital and I innocently thought a discharge meant he had recovered. After a month or so I started to realise that things were not quite right and, after a few months, we were told by the paediatrician that he had developmental delay. So perhaps that meant he was a little slow for now, but surely he would eventually catch up?

After a period of time I started to realise that he might never catch up in terms of his developmental milestones and the compensation seemed to be more and more professional people becoming involved in our lives. My awakening to this world was slow but was becoming very, very real.

### Fear of the unknown

When a disability happens in your family it is like you wake up in a place you never knew existed, a place known as "service land", where things are often done to you rather than with you. The search for an accurate diagnosis takes over your life. Perhaps, if you have a name for what is wrong, this will give you a passport to the support and services that you need. As a family you seek out as much information as you can, fighting the system to get the best life possible for your child. You start to go to meetings, conferences and meet many different people.

You become angry and frustrated with things not working, as the very system that is there to support you seems to let you down time after time.	58
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You meet other families who are all having similar experiences and then you discover that the very system put there to help us feels like it has put families in competition with each other.	60
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You discover the health and social care system is neither equitable nor transparent. There is no logic to the way it works and it feels like “those that shout the loudest get the most”. The very system itself – designed to promote independence – seems to make you more dependent, by reinforcing that “the state knows best”.	62
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For the first time in the history of the world, many (perhaps most) people with learning disabilities are likely to outlive their family members, who, traditionally, have provided much of the support they have received (Walker and Walker, 1998). The increased demand on the state will put an immense strain upon the system, but who is really thinking about the long-term implications, not just for the state but for the individual – the citizen? We have overcomplicated the lives of people with learning disabilities and their families and need to bring people back to ordinary lives, not just the chosen few living extraordinary lives. The time has come for a very different conversation, a conversation which frightens us to death, which works out how the people we love and care about have a good life which is sustainable when we are no longer here, because as we all know love simply won’t be enough.	67
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<b>The welfare state is creaking</b>	79
Who knows? Maybe my life belongs to God. Maybe it belongs to me. But I do know one thing: I’m damned if it belongs to the Government! – Arthur Hoppe.	80
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As family members we are driven by two very clear emotions – love and fear. We can describe all day the love we feel for our children but it is much harder to talk about the fear. It is the ultimate fear – what will happen to the person you love so much when you are no longer around? Who will know them inside out like you, who will ensure they have everything they need and who will fight their corner?	82
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For many years we have invested in creating a system where people have become more and more dependent. The state system has become the answer to everything as it has attempted to be all things to all people. The system cannot continue in this way, it needs to allow, nurture, encourage and evolve wherever possible a new culture of helping people to help themselves.	88
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When my son was very young a senior health visitor gave me some very good advice. She told me that no-one was really interested in my son but me. At the time the words seemed harsh and extremely hurtful but as time moved on I started to discover she was right. The only consistent people in the lives of people with learning disabilities are their families. However, as a person gets older, family networks diminish and many people end up with the only people in their lives being those that are paid to be there.	92
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So how are we investing in real families, in family leadership, in creating a sustainable life for people when their families are no longer around? We have for years fudged the issue with the “carers agenda”, patting families on the head in a patronising, meaningless way that has offered no real resource apart from the odd head massage or pedicure. The truth is that we need practical help and information to ensure the lives of our grown up children are as good as they can be.	99
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This is not to criticise the many good examples of service providers doing a great job for people without or with limited family or friends. Rather it is about finding ways of capitalising on the care and love families provide to get the best outcomes possible for the person who needs support. My belief is that it is positive relationships which make change happen rather than enforced rules or policies.	106
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<b>Families making change happen</b>	112
Never doubt that a small number of thoughtful committed citizens can change the world; indeed it is the only thing that ever does – Margaret Mead.	113
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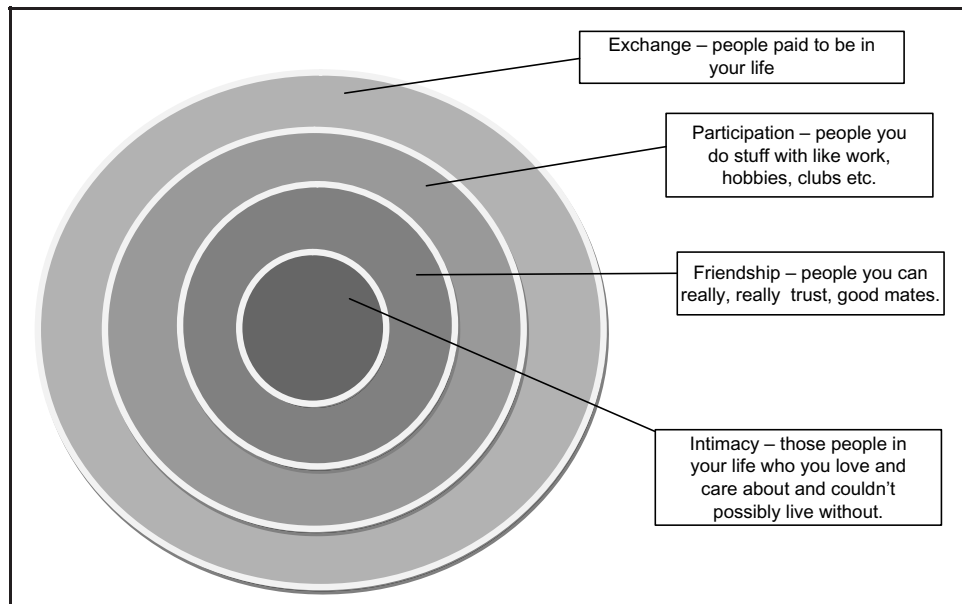
Partners in Policymaking and associated courses have offered individuals and families an excellent lesson in helping themselves. More recently the All Together, Better course has enabled professionals to learn alongside individuals who need support and their families. The course takes people on a journey of discovery which gets them to look at why things are the way they are. It gives people the tools to make change happen in their own lives, builds up their confidence and self-esteem to influence, make changes and help others in their community. The course brings the best speakers from across the world and gives a real flavour of what is possible. There is no doubt that it inspires, motivates and can visibly change the attitudes of the participants to their own families, each other and most importantly themselves.

Partners in Policymaking first started in the UK in 1996 and was based on the USA model. I was privileged enough to be on this first course and for me it gave me the practical tools and help that I needed to do what felt right in my own heart. The course has helped hundreds of people since, as it has been delivered in various formats across the country and has been funded by many different Local Authorities. Partners started me off on a journey in which I learned about "circles of support". The first circle of support was the "Joshua committee" which was made up of John O'Brien, Jack Pearpoint and Marsha Forrest – now internationally renowned leaders in person-centred support for people with learning disabilities. John, Jack and Marsha had met Judith Snow, a very bright and articulate young Canadian woman who happened to have a disability. Judith was controlled by the residential care home in which she lived and was struggling to live an ordinary life, like being able to stay out after 7 pm To cut a long story short they created a circle of people around Judith who could help her to get out of this environment and live a good life (Pearpoint, 1991).

I was fortunate enough to meet Judith and she inspired me to start to think very differently by doing a very simple exercise. She asked us to draw four circles, one inside each other (Figure 1).

She then asked us to put the initials of people in each of our own personal circles. Then she asked us to do it for our children. The difficult thing to get your head round was that our children had more people in their life paid to be there, with very few people they did stuff with, no real friends and a few folk who loved and cared about them that would potentially diminish over time. The bleak future was staring me right in the face. Judith made us all think by asking us how long we were prepared to wait for a friend for our child to knock on the door.

**Figure 1** Circle membership map



She pushed a hard message to us that unless you are there you won't be included and sometimes you have to invite people into get involved in your son's or daughter's life. I contemplated the idea for a while and then took the plunge.

We invited good people we knew to come and help us do some thinking about Joe's future. We got Lynne Elwell and Paul Taylor to facilitate the circle and had a couple of meetings. The circle worked really well and we started to think as a group of people about future possibilities. We developed a vision for Joe using person-centred planning tools. Joe would have his own house, his own car and would be doing something like a job – yet in my heart as much as it was a goal or dream I did not believe it would actually come true. At this time Joe was only eight years old and I was only 30, I had just had my third child. Perhaps, I did not have a sense of my own mortality or perhaps I simply did not want to think about it.

As much as the circle was fantastic I was the one that still had to organise everything and I started to feel really tired. As Joe reached the age of 12 the next few years became a blur and I felt I was yet again having to fight the system. I mustered up the energy and got Ruth Gorman, from Helen Sanderson Associates, to facilitate the circle as we were in a bit of a crisis and Ruth did a wonderful job. Ruth re-invigorated the vision and the circle really started to come together. Joe was fortunate to be one of the first people in the country to self-direct his own support. He now has a great team of people supporting him, his own home, his own business, his own car and a great life, but in reality could it be sustained?

### Feel the Fear and do it anyway

A life spent in making mistakes is not only more honourable but more useful than a life spent doing nothing – George Bernard Shaw.

The future is the scariest, most difficult thought for most families. Many older family members were told for years that their child would die before them. Many still hope for this because the thought of dying with your adult child being supported by the state is a fear they simply do not want to face. However, we must get to grips with this fear because, for many of us, it will happen. We need to understand that the biggest disability most people face is isolation and loneliness. Being “disconnected” has a significant impact on any individual's mental health and well-being. Yet what are we doing to prepare for the inevitable? This question bothered me significantly, what would happen to Joe in the future and who would know his real story?

When I say “who will know his story” it is because I am convinced that the assessments gathered by the State over the years will not reflect the real Joe. An example of this comes from an incident about 18 months ago when Joe visited London with a couple of friends and his Personal Assistants. Joe has an inexplicable obsession with carrier bag handles, he is a man of quality who especially loves Sainsbury's carrier bag handles. They all decided to go to the South Bank and so got on the Underground. As Joe stepped onto the train there was a man taking a small party of school children on a school trip and, in his hand holding the rail above him were his sandwiches in a, you have guessed it, Sainsbury's carrier bag! Joe launched himself at the man, ripping the bag from his hand. The look on the man's face was one of being in extreme danger. Immediately Joe's team stepped in, caught the sandwiches, offered the gentleman a new carrier bag and then explained. Just imagine, for one moment, the people supporting Joe did not really know him. My guess is that the incident would have escalated out of control and Joe could have been taken away, never to be seen in the community again. This is not an extreme reaction, we know similar things have happened to many people over the years.

My experience of seeing what happens to individuals without a plan scares me senseless. I heard the story of a dad dropping dead in the supermarket while supporting his daughter with learning disabilities. It was only in the accident and emergency department of the local hospital that it was recognised she had a learning disability. She was quickly whisked off to the local respite centre where she could only stay for ten days, then she was shipped into a hostel where the average age of the more than 25 residents was 64-years-old. This young woman was 24. Eventually, her brother, who lived in the other side of the country, tried to help get her out. He wanted her to move closer to him but his Local Authority would not fund this.

He then asked her residing Local Authority if they would fund her to live near him but this was also refused. After several years she moved to a house with friends she knew from school and all was well, or at least better. Perhaps, with advance planning (confronting the fear) she could have stayed in the family home with support.	229 230 231 232
It was this family's story that pushed me to ensure that this would not happen to Joe. I discovered an organisation called PLAN based in Canada. In Vancouver, in 1986, a group of parents of young adults with learning disabilities met informally and discussed their experiences. They found they had two major concerns in common: "What happens when I am gone and how can I ensure he/she has a good life?".	233 234 235 236 237 238
Those parents found their concerns were common to almost all parents they met who were in the same situation. As a result they organised themselves and secured some funding. Three years later the first PLAN organisation was established in Vancouver. Over the next 18 years PLAN groups were created in provinces across Canada. In 2003, the PLAN Institute ( <a href="http://www.planinstitute.ca">www.planinstitute.ca</a> ) was established in Vancouver. The Institute became the national "umbrella" organisation that binds those groups together. It promotes the organisation's core values, shares learning and good practice, provides training and produces resources. The Institute has both a national and an international profile. It is a voice for the PLAN movement, and has the authority to influence national government. It is consulted on national policy. It has, very recently, influenced a significant change in law to benefit disabled people and their families.	239 240 241 242 243 244 245 246 247 248 249
While PLAN has developed and diversified as an organisation, its original and ongoing focus has been to establish sustainable circles of support – circles which would help to ensure both a good life now for the disabled person and the security for the family of knowing that, when they died, there would still be people looking out for their son or daughter. I was intrigued and so gathered a few families together, got some funding and went off to Canada to learn in detail how it would work. We also spoke to people in Scotland who had set up an organisation which did something similar called Equal Futures ( <a href="http://www.equalfutures.org.uk">www.equalfutures.org.uk</a> ). They provided real insight into the difficulties of developing the concept in the UK and shared the highs and lows of making it happen.	250 251 252 253 254 255 256 257 258
After an enormous amount of research we have started to develop the concept across England as Our Futures. The co-ordination of this programme is sat in the self-sustaining family led organisation I set up over 12 years ago – Embrace Wigan and Leigh ( <a href="http://www.embracewiganandleigh.org.uk">www.embracewiganandleigh.org.uk</a> ). The concept is simple. We raise awareness of circles of support and how they can help. We identify individuals or families who would like a circle. We then find a facilitator to match the individual and their family (if there is a family). The deal is that, if possible, the family pays a small fee to Our Futures for each circle session facilitated. Why pay? – well, nothing in life comes for free, and if you pay for a service you will complain if it is no good. For the small fee Our Futures organises and trains, mentors and pays the facilitators – and covers its own costs as an organisation. As circles are formed around a number of individuals, the families are invited to come together to set up their own little Our Futures group to provide mutual support. As the group feels more confident it can take on the responsibility of co-ordinating facilitators with support from Our Futures or another group – it is all about sharing and passing on the concept, ideas and support. As each group grows each member is asked to contribute to keep the group going – this may be sharing co-ordination tasks, holding social events for the groups to meet or simply by bringing the biscuits. As the groups evolve families can share with each other how the circles work. Each group is encouraged to have a mix of generations involved but to keep small. So, as family members get older, responsibilities are passed to other group members to keep the co-ordination working and the circle alive. These younger group members will, in turn, expect the next generation to do the same for them.	259 260 261 262 263 264 265 266 267 268 269 270 271 272 273 274 275 276 277 278 279 280
Already we have developed more than 30 circles for individuals and families with committed and trained facilitators making the circles happen. We have a wide variety of families from those with very young children to older parents with adult children and those who have lost a partner through ill health. The circles have, in some instances, moved mountains, but often they simply give people a feeling of security or cheer them up. For our family,	281 282 283 284 285

joining the infrastructure of other families is what will keep Joe living a good life. It is early days, but what we are seeing is a very real concept providing something that has never existed before. The people at the heart of the circles and their families and friends feel much safer and secure. They say they cannot believe how such a simple concept seems to be so effective.

Of course, the circles concept is not new but this process makes it more accessible to everyone – the challenge met by Our Futures and similar groups is: if you want a circle and you do not know a soul we can help you to build one. The circle's effectiveness springs from its being owned, loved and cared for by individuals who need support and their families. It may not be the right solution for everyone and, certainly, should not become a standardised practice. Our Futures is a concept and idea for people to think about and is not the only way to develop a circle of support. However, it provides an infrastructure for offering people peace of mind should they wish to take it.

### Finally

My son, Joe, is now 23-years-old. I hope to spend many more years being able to fight his corner. But, like all parents, I will not be able to do this forever. This article is just a story, really. It is a story of how I realised how hard it was to get Joe a good life and how frightening was the thought of not being around to make sure he was ok. In my struggles and fears I have learnt a lot. It is possible to set things up in a way that works better for Joe, even though it may need constant vigilance. It is possible for Joe to have a good life. It is even possible for me to feel more secure about what happens when I am gone. We all want the government to spend more money and provide better services. But, in the end, such services do not provide security. People provide security. Joe's security, and my own, depend upon his being at the centre of a network of people who care about what happens to him and will continue caring, even after I have gone.

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