**Love is simply not enough – by Caroline Tomlinson**

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

**About the author**

*Caroline Tomlinson lives in Lancashire with her husband Robert and three children Joe, Rosie and Jacob. Caroline became involved in the world of services as her eldest son Joe contracted meningitis and was left with a huge range of complex disabilities. In her attempt to get a good life for her son Caroline home educated Joe, developed a wide range of inclusive play opportunities, accessed a host of learning opportunities including Partners in Policymaking, got several user led organisations off the ground and was one of the co-founders of In Control. Caroline’s professional career has been wide and varied from starting out as a riding instructress, to a purveyor of fruit and vegetables, she then settled into working within services to make an ordinary life for not just Joe, but for the many people who need support. Caroline has worked in local authorities with adults and children’s services, PCT’s and the third sector in many aspects of community development. She has presented internationally, wrote many articles and has written the book The Essential Family Guide. Caroline inspires, motivates and talks from the heart, but most of all makes it real as she lives the concept on a daily basis.*

On the 11th April 1989 I was sat in an isolation ward in Wigan Infirmary being told my six-month-old son 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 thoughts inside my head were simply ‘it doesn’t matter’, I wanted my baby to survive, whatever the cost. I knew that I loved my child so, so much even though he has been hurt once by this terrible disease, I will never let him be hurt again. My reaction was to hold my child to nurture, protect and love him forever, but would love be simply 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, after a visit to the paediatrician we were told 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 may 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 admittedly 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 ‘service land’, where things are often done to you rather than with you. The search for an accurate diagnosis takes over your life, ultimately knowing that if you have a name for what is wrong, this will give you the passport to the support and services that you need.

As a family you seek out as much information as you can believing you have to fight 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.

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. You discover the health and social care system is neither equitable nor transparent. There is no logic to the way it works and in simple terms it feels like ‘those that shout the loudest get the most’. The very system itself - designed to promote independence - seems to make you more dependant on the system, by reinforcing that ‘the state knows best’. Yet we have the biggest population across the western world of people with learning disabilities who are likely to outlive their family members, this has never happened on such a huge scale before (Walker & Walker, 1998). The demand on the state will really put a 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 over complicated 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 literally 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 simply LOVE won’t be enough.

**The welfare state is creaking**

**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**

As family members we are driven by two very clear emotions one is love the other is fear. Love we can describe all day for what we feel for our children, the fear however is much harder. I believe the fear is the ultimate fear of 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?

For many years we have invested in creating a system where people have become more and more dependant, even to a point where they have had to ask permission for everything they do. 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 those who are willing to help themselves.

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. If we think about who are the consistent people in the lives of people with learning disabilities the only people that really are is the family. What we also know is that as a person gets older the family networks start to diminish and for many people they end up with the only people in their lives are those that are paid to be there.

Yet 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, un-meaningful way that has offered no real resource apart from the odd head massage or pedicure. The real fact is that we need practical help and information to ensure the lives of our grown up children are as good as they can be.

**Families making change happen**

**“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**

Partners in Policymaking and associated courses have offered individuals and families an excellent lesson in helping themselves. 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.

The course first started in the UK 1996 which 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.

My personal example of this was when I had experienced Partners in Policymaking it started me off on a journey, and I learned about circles of support. Circles of support first evolved in Canada by the Joshua committee which was made up of John O’Brien, Jack Pierpoint and Marsha Forrest – who are now internationally re-known leaders in person-centred support for people with learning disabilities. John, Jack and Marsha had met Judith Snow, a very bright and articulate young 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 stop out after 7pm. 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. Ref: From Behind the Piano – Judith Snow.

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 4 circles, one inside each other. See diagram below:-

Exchange – people paid to be in your life

Participation – people you do stuff with like, work, hobbies, clubs etc..

Friendship – people you can really, really trust, good mates.

Intimacy – those people in your life who you love and care about and couldn’t possibly live without.

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. She pushed a hard message to us that unless you are there you won’t be included and sometimes you have to invite people in to get involved in your son or daughters 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 possibility. We looked at a vision for Joe by using some person centred planning tools and the vision said that 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 didn’t 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 so perhaps I didn’t have a sense of my own mortality or perhaps I simply didn’t want to think about it.

As much as the circle was fantastic I was the one that still had to organise everything and 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 how sustainable was it?

**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**

So what about the future – it is the scariest most difficult thought for most families. Many older family members were told for years that their child will die before them – and we know many hoped they would because the thought of dying with your adult child being supported by the state, is a fear that many people simply do not want to face. The fact remains that we are being out lived by our loved ones by significant numbers and so it is a fear we need to get to grips with. We need to understand that the biggest disability most people will face in this country is isolation and loneliness and by being disconnected has a significant impact on any individuals mental health and well-being. Yet what are we doing to prepare for the inevitable? This question bothered me significantly as I only know too well we don’t die in chronological age, 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’m convinced the assessments gathered by the state over the years will not reflect the real story about Joe. If people don’t really know him well what will happen long term in the future? An example of this is when about 18 months ago Joe visited London with a couple of friends and his PA’s. Joe has an unexplainable 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 tube, as Joe stepped on the tube there was a man taking a small party of school children on a school trip, in his hand holding the rail above him was his butties (sandwiches) in a, you’ve guessed it, Sainsbury’s carrier bag! As Joe stepped on the tube he launched at the man, the look on the man’s face was one of being in extreme danger, Joe grabbed his bag, ripping it from his hand. Immediately his team stepped in, they caught the butties and offered the gentleman a new carrier bag and then explained. Just imagine for one moment the people supporting Joe didn’t really know him, my guess is that it would have escalated out of control, Joe could have been taken away never to be seen again. This isn’t an extreme thought, we know it has happened to many people over many years, but here is our chance to get it right.

My experience of seeing what happened to individuals without a plan scared me senseless. I knew a story close to me where a dad supporting his daughter with LD dropped dead in the supermarket. It was only in A&E it was recognised she had a learning disability. She was quickly shimmied off to the local respite centred where she could only stay for 10 days, then she was shipped into a hostel where the average age of the 25 plus residents was 64-years-old. This young woman was 24-years-old. Eventually her brother who lived at the other side of the country tried to help her out but was in a difficult situation, he wanted her to move close to him but his LA wouldn’t fund her. He then asked her residing LA if they would fund her to live near him but this was refused too. It was a catch 22 situation and was very difficult to all concerned. Eventually after several years she moved in a house with friends she went to school with and all was well, but perhaps if only her dad had planned she could have stayed in the family home with support.

It was being involved with this family that pushed me to ensure that this would not happen to Joe. I continued to search and found 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?*

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 a research grant. Three years later the first PLAN organisation was established in Vancouver. The model was again influenced by progress of a group called the Joshua Committee, set up to support a disabled woman in Toronto (Judith Snow) to have an independent rather than an institutional life.

Over the next 18 years PLAN groups were created in provinces across Canada. In 2003, the PLAN Institute was established in Vancouver. The Institute became the national ‘umbrella’ organisation that binds those groups together. It promotes the core values, shares learning and good practise, provides training and produces resources. The Institute has both a national and an international profile. It is a voice for the PLAN movement, and as such, has authority and weight enough 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.

Further information available at [www.planinstitute.ca](http://www.planinstitute.ca)

They had developed sustainable circles of support for many families across Canada that potentially could be replicated in the UK. This model seemed to offer a positive solution to get circles happening for those families who needed them, but seemed to have a model that could be sustained long-term and wasn’t reliant on the families always being there. They had evidence of circles working in the long term and had developed a sustainable funding strategy that wasn’t reliant on the state.

 I was intrigued and so I gathered a few families together, we 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. They gave me a real insight to developing this concept was not going to be easy in the UK and they taught us the highs and low’s of making it happen.

After an enormous amount of research we started to develop the concept across England which we call **Our Futures**. We have handed the co-ordination of this programme over to a strong self-sustaining family led organisation – Embrace Wigan and Leigh supported by In Control.

**So What is Our Futures?**

Our Futures is as relevant to families of children with disabilities as it is to families of people with older age related needs, as it is to families of adults with learning or physical disabilities. Its aim is to develop local groups who will be supported and trained to provide carer/family peer support initially **to themselves and then to other local** people with:

* **Support and advocacy**, development of family leadership skills to support themselves and others e.g. through periods of change
* **Future Planning,** supporting families to plan for the future and develop circles of support, considering e.g. wills, trusts, guardianship, agreements.

**Personal Support Network Development.** Supporting the development of an independent circle of support for the person they care for.

**Community Connectors.** Some people need specific support to be able to develop social networks/friends and reduce reliance on paid carers. Not all people can go out and do this by themselves. The paid role of community connector helps people to do this and can be purchased with a personal budget.

**So how does Our Futures work?**

It is well known that for many people, the support and expertise of people who have been in a similar situation to themselves is key to supporting them positively through periods of change, we often call this peer support. Enabling these approaches also helps to increase the social capital of local communities and links to recent national policy development on ‘Big Society’.

Our Futures is a tried and tested family-led project based on the last 20 years of work done by PLAN in Canada. It was set up to address two major concerns of family carers:

‘What happens when I am gone?’ and

‘How can I support my relative to have a really good life?’

The support from Our Futures shares, nurtures and prepares families to, in the first instance, make a difference to their own lives and to have peace of mind about the future of the person that they care for. Together the families may form a group together and an overarching circle of support, with the commitment to each other that should something happen to any of them that they will be there to continue to offer support to their loved one.

Circles of support are made up of people who are not paid to be in the person in the centres life, and are there because they know, love or care about that individual. Circle members can help the individual with a disability and their family to plan for the future, to set up discretionary trusts, to advocate on their behalf, to be around in a crisis to assist or simply to be involved socially. Should something happen to their family members their role will be to ensure that the individual in the centre continues to lead a good life. The wider work of Our Futures is also to ensure families receive good legal advice when setting up wills and trusts and future planning.

The **sustainability** of the project emerges from those families securing a future for their loved ones, exploring natural support mechanisms and being less reliant upon statutory services. They then share their experiences, knowledge and training with new families, mentoring them to set up their own circles of support and in turn some will support other families.

The end of this year (2010) will see the launch of the first UK toolkit for families. This will be grown over time, adding stories etc, including the learning from the various groups across the country and will be available on the My Life section of the [www.shop4support.com](http://www.shop4support.com) website. The national support network is being developed to share experiences, solutions and strengthen the sustainability of the programme long term.

**So why is it so important?**

Based on work over 20 years in Canada, PLAN found that:

* When families make sound long-term plans (practical and legal) for their disabled relative, that person is much less likely to need care triggered by crisis
* People are healthier, happier and less service dependent when they have lots of people in their lives who care for them
* The model consistently involves members of the community in long term volunteering.
* Families who have taken part in family leadership training are much better at communicating with statutory services.

Our Futures, its values and practises and the model itself, is in keeping with what is now an international movement. Across Canada, USA, Australia, India and parts of Europe the values of caring citizenship, contribution, self-reliance and equality are shaping future provision of social care and the range of opportunities available to disabled people, older people, and their families.

The issues are clear:

* Our welfare state cannot sustain its level of involvement in the lives of disabled people
* Disabled people and their families want ‘ordinary’ lives, rights and equality, with less statutory sector involvement.
* Evidence to date demonstrates that disabled people rarely fulfil their full potential within a traditional model of social care. The more freedom people have the more they can achieve
* Evidence to date demonstrates that communities can, and will, support their members, if allowed to do so. Our communities need opportunities to develop and practice caring citizenship.
* Relationships provide security. The more people we have in our lives that care about us, the less likely we are to be abused.
* Families supporting disabled people usually want to continue to do so. They need good quality support to avoid burn out and breakdown.

Studies done over two decades involving more than 37,000 people show that social isolation – the sense that you have nobody with whom you can share your private feelings, have close contact with – doubles the chances of sickness or death. Daniel Goelman

It is a model that offers positive responses and solutions to the challenges identified above:

* It requires initial grant funding only: self-sufficiency is key to its existence and independence. Beyond contributions from families, corporate funding is pursued, bringing new revenue into the third sector.
* It asks a different question ‘what is a good life’. It offers families and in turn communities the opportunity to focus on gifts and contribution of individuals with disabilities, rather than needs, difficulties and dependency.
* It is as relevant to families of children with disabilities as it is to families of people with older age related needs, as it is to families of adults with learning or physical disabilities.
* Evidence from Canada and Australia demonstrate both its value to families and its potential to contribute to sustainable positive change within communities.
* It will be a national social enterprise supporting development of further local social enterprises, each bringing and sustaining caring citizenship.
* It brings to the UK third sector the positive ethos of abundance; that the sharing of learning generously and openly strengthens organisations and encourages reciprocity and genuine partnerships.

Cleaving to the principles and practices of the Canadian model, Our Futures works to embed the concept of caring citizenship into our culture and our communities. Through family leadership, provision of expert tailored advice and networks of support, its members will be equipped to plan for the future, and live their lives with as much support as necessary and no more than is needed i.e. to achieve peace of mind and a good life. Each group will evolve to be a permanent and forward thinking family led resource of the highest quality.

This model of tailored and individualised support is not one that lends itself to numerical targets or rigid timescales. Even with assistance, relationships take as much time to develop as they take. Community Connectors do not have a timeline with a completion date for establishing network of support – as is not an effective measure of success. Families, when undertaking future planning, take the time they need to work through the emotionally charged issues that are involved.

Our Futures measures its success by the impact of services on families who use them, and on the willingness and enthusiasm of families to give their time to the organisation, and its ability to attain financial self-sufficiency.

Launched less than two years ago we now have six groups working in various places across the country who are made up of small groups of families with one core common aim – to secure a good life for their son and daughter when they are no longer here. Circles are evolving and are getting stronger by the day – the small groups are becoming self reliant and offer mutual support to each other. Families are learning the importance of inviting people to be involved in their family members life, planning for the future, developing wills and trusts, looking in to the Mental Capacity Act, handing over their stories to others and preparing for the inevitable, but most importantly a sense of peace of mind has started to evolve.

Interest in the model is certainly gathering with some new groups starting up in the East Midlands very soon. A report will be written of progress to date by the end of the year and can be found on at [www.in-control.org.uk](http://www.in-control.org.uk)

Here are some of the stories so far:-

**Pauls Pondering Posse**

Paul has a circle that has been set up in the last few months, so that his mum and dad and their non disabled daughter could have peace of mind if anything should happen to mum and dad. They had wanted a circle for years but didn’t think it would be possible to do. The big issue for them was who would you ask and would people be interested. The facilitator Kevin really made this work and reassured them throughout the process. What they never anticipated was that when they set up the circle there would be so many on-going issues that they were struggling to deal with; the circle has really helped on a practical and emotional level and is making the whole family feel much more confident about the future.

**Jenny’s Jolly Jaunts**

A circle has been set up for Jenny, a young lady with very complex needs. She’s in her final year of college within a special school setting. Both mum and dad were very anxious about their daughter’s future and hadn’t got confidence in a social worker giving the family the best options for their daughter. Where she lives, transition social workers still only get involved with the individual six months before they leave college at 19.

After just two circle meetings and lots of tasks completed by the circle members this young lady has more options available now than she can fit into a week. Ironically, most of the activities are part of universal services which is fantastic considering this young lady’s complex disability. We held a circle meeting last night and mum and dad said they are quite overwhelmed by what the circle has achieved in such a short space of time, and they couldn’t measure just how much pressure the circle has taken off the family.

**How long do we wait for the Invite?**

A single parent heard a presentation from Our Futures and took the information away with her. She then got in contact with us four months later. She wanted a circle for both her son and daughter because mum has started to have concerns regarding the future and if anything should happen to her. Both her son and daughter currently live at home and have no plans for moving out in the future. Both her son and daughter have a learning disability, but if anything should happen to mum they would be able to live together without support except for someone popping in now and again. What mum’s main concern is, that If anything should happen to her son and daughter they wouldn’t financially be able to continue living in their current home. She feels that if they need to move they would be left vulnerable and could be open to financial abuse. At first she was struggling to think of anyone who would want to sit on a circle. However, after spending a bit of time with the coordinator she came up with 5 names. We have held one circle meeting to date. One circle member said we have been waiting to be invited in because we didn’t know how to approach you. Mum said that she didn’t ask in case people thought she couldn’t cope. Again, at the circle meeting, day to day issues came up and mum had tried to sort some of the issues out but was struggling. Although it was the first circle meeting 3 members have taken on tasks to help the family move forward. These issues have all now been addressed.

**What about people whose family are not interested?**

Carly has just turned 22 years old and has had a life of shared care between the state and her family. Carly has a moderate learning disability and went to a special school, but her support needs were heightened by her chaotic family life. Carly spent much of her childhood between council respite units and living at home. When Carly turned 18 years old her family were persecuted by a firebomb at their home and this separated the family. The only option was for Carly to live in a hostel with 36 other people who all were significantly older than her. Carly was extremely unhappy, she didn’t know many people and her family no longer wanted contact with her. Having known Carly for several years to get out of the crisis situation, we felt the best thing would be set to up the circle, even though this would be our first it was worth a try. The circle was made up of several people who had known Carly in school and different places she went to. In the first instance the circle managed to secure some direct payments and manage the payments so she could have at least have some quality time with personal assistants outside of the hostel. Eventually the circle managed to support her move into her own home and have been critical in terms of ensuring she can access and contribute to her community. The circle is as strong as ever 4 years down the line and has supported Carly with the of struggles where she lives and who she lives with. The circle are helping Carly look for an alternative place to live in the future, but are supporting her to get it right. They assist her with her making choices on how to spend her money, getting her staff team to understand her and have recently enabled her to meet back up with her Mum again. By no means is Carly’s life sorted but the circle has her vision at the heart of everything they do.

**What happens when I’m gone?**

Brendan is in his 40’s and found himself in residential care. His Mum had died years before and his Dad had just died suddenly. Brendan wanted a circle but the people paid to be in his life resisted like anything. To cut a long story short the circle has finally got going after negotiating long and hard with the paid staff, and is working on a plan for Brendan to live with someone out of the residential care unit that he gets on with really well. They are looking for property near where he used to live and hope to be in their own home for Christmas.

**What happens when I’m long gone?**

Bernard is 62 and his family have either died or live abroad. He has lived on his own for years and has been supported by a provider who recognised he didn’t have many people in his life, just paid support. A circle started to evolve as the facilitator recognised some of Bernard’s interests. Bernard was an avid world war fan and so the facilitator has got a local group of veterans involved, some folk from the local supermarket distribution centre and other local people. The circle are in the early stages of building a relationship with Bernard, but already he is chatting more, is certainly more sparky and a glint seems to have some into his eye.

**So to conclude**

The circles have in some instances moved mountains, given people a feeling of security or have simply cheered people up. For our family 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 that whatever shape or form the circle takes, it is providing something which has never existed before.

The people at the heart of the circles and their family and friends are feeling much safer and secure. They say they can’t believe how such a simple concept seems to be so effective. The effectiveness we believe is that it is owned, loved and cared for by families. We don’t profess it is the right solution for everyone nor do we think it should become a standardised practice. Our Futures is a concept and idea for people to think about and certainly is not the only way people can develop a circle of support, however it provides the infrastructure for offering people peace of mind should they wish to take it.

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