



# DEVELOPING FAMILY LEADERSHIP

A Discussion Paper on Personalised Transition  
from The Centre for Welfare Reform.

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# 1. INTRODUCTION

There are four key components to Personalised Transition:

- Family Leadership
- Curriculum for Citizenship
- Integrated Budgets
- Co-ordinated expert support

In this paper we explore Family Leadership, highlight some key steps to encourage its growth and outline some of the practical ways in which progress towards Family Leadership is being made across the region.

Families can only thrive if they are connected to, valued by and have a sense of belonging in their local communities. As we forge new pathways to support disabled families - pathways based on fairness and equality - we do well to remember the central currency of family life is love.

**The majority of parents of disabled children love their children above all else, and simply want to do the best they possibly can for them:**

*There was no place for my child. I was on my own. It was up to me and I hadn't a clue. But I had made my mind up about one thing, I was going to love my child. She wouldn't let me hold her hand or touch her, but she did accept me holding her in my arms to love her.*

Parent 2002 (Telling Our Own Stories, Parents with Attitude)

*I knew her condition was serious and her prognosis poor but, to me, she was my first born, beautiful child. Every time I expressed my joy to the staff at the hospital, they said, 'She's denying reality'. I understood the reality of my child's situation, but for me there was another reality*

Parent (cited in Kearney and Griffin p.585)

At no point in our history, either before or after the creation of the welfare state, have disabled families been given support enabling them to get on

with their lives without having to struggle and fight for the extra help they need to experience ordinary family life. The result of this struggle frequently adds to the difficulties families face, rather than making things easier for them.

State assistance for disabled children and their families is rooted, through legislation, to child protection and 'children in need' processes. Social care is expected to deliver support through an opaque, subjective assessment system based on parents demonstrating they are struggling, and heading towards family breakdown. This means that parents have to collude with the negative view from the state that their disabled child - on grounds of impairment - is the problem within the family. The system demands that the family becomes defined by impairment - the disabled child is the problem; parents and siblings become carers and young carers.

The underlying message of this system of support is that the disabled child needs to be absent to allow the family to function 'normally'. This has the effect of fracturing rather than supporting family relationships and parents are given the idea that they need the help of 'experts' to bring up their child.

This experience, alongside the prevailing belief in our society that impairment is a 'bad' thing, contributes to an ever increasing sense of disempowerment. By the time a disabled child reaches their teenage years, parents will often have internalised the message that their child's impairment is 'too much' for a family to cope with - both physically and emotionally - and they need the help of experts. This contributes to a loss of autonomy and a corresponding increase of dependency on the state.

State support for disabled adults is similarly weak around entitlement: at the age of 18 a young person with learning difficulties is entitled to have a community care assessment but has no corresponding entitlement to have their basic support needs met. In addition to this, their legal status as adults changes the way in which their relationship with their family is viewed. As a consequence professionals are in the position of being able to override parental wishes on the basis of acting in the best interest of the young person.

Although the legal framework changes from child to adulthood, neither supports the family unit as a whole or trusts parents to get on with their job. Parents are in the unenviable position of always being in relationship with people who have power over them in relation to their son or daughter - power to give or withhold information, time and resources.

# 2. FAMILY LEADERSHIP

We use the term Family Leadership deliberately. Family Leadership is based on the premise that all family members are of equal value and that family dynamics change as children move from one age and stage to another. This has particular relevance for both disabled and non-disabled children in the family.

## 2.1 DISABLED CHILDREN

Family Leadership depends upon parents championing the voice and independence of their disabled sons and daughters. This looks very different when a child is under five and when that same child is over eighteen. Our culture makes championing the voice and independence of our disabled children very difficult. Most families will advocate for their disabled child with the best of intentions but not all families will necessarily encourage independence, positive aspirations or be objective and enabling. The ability to take this approach depends on many things, including:

- an understanding of our disabling world
- personal beliefs and values
- inner strength and resilience

Parenting is not an easy job! And the added dynamics of impairment and disablement make the relationship between parent and disabled child extremely complex. Family Leadership depends upon parents supporting their sons and daughters to find their own identity, make decisions, make choices, feel comfortable with support, have aspirations for their future and to make and keep friendships. This is only possible when parents deconstruct the prevailing message that to have an impairment makes people 'less than' and construct alternative lives based on the belief that all people are of equal value.

The central priority for health, education and social care must be to ensure that every member of the family members strengthens their own resilience. The family is the bed-rock for the well-being and development of the child. And it is the development of the family's Real Wealth which will enable it

support and nurture the disabled child. [See Figure 1 and Pippa Murray's paper *A Fair Start* for a full discussion of this concept.]



Figure 1. Real Wealth

It is often assumed that paying attention to the family means denying the voice of the child. However, including the voice of parents does not necessarily mean ignoring the voice of the disabled young person. But it does mean avoiding naive over simplification of child-adult-family dynamics and respecting families – parents, siblings, grandparents, aunts and uncles - as one of the foundation stones of a good life. The fact that young people and parents have different ideas about what is best is a common dynamic within families. Family Leadership depends upon both young people and their parents being respected, valued and having opportunities to explore the options from their own perspective.

At present parents find themselves in a lose-lose situation. Parents with high aspirations for their children find themselves constantly at the mercy of professionals asking them to be 'realistic':

*They (professionals in education, health and social care) tell me I can't do this or have that because it would set a precedent. They tell me the world is not ready for me or my son yet! How can that be when we are in the world now? They tell me they admire me and understand and would like to help me, but... And the buts go on forever.*

Parent, 2010

**Other parents report that professionals find them lacking for the very opposite reason! They are defined as the problem because they are viewed as not having high enough expectations, being over protective and unable to let go. This is particularly common as young people leave school and move into adult life:**

*I don't think they should be the ones telling me what to do. What do they know about my life or my son's life? They keep talking to me about independent living. That is all well and good, but I am worried he won't be supported properly. I cannot let him go just anywhere. He is so vulnerable and people need to know him really well to make it OK for him. I don't know anyone outside the family who knows him really well.*

Parent, 2011

Which ever way they are viewed, parents seeking help can find themselves defined as part of the problem rather than part of the solution. **Family Leadership is based on the premise that families are the experts in their own lives and demands that the main function of support agencies is to increase their resilience.**

Family Leadership does not mean families doing everything for themselves. Instead professionals must forge a radically different relationship with families. Professionals have power over families, for instance they are often gatekeepers to vital resources. Those holding power must recognise that fact and commit themselves to changing the balance of power or, at the very least, to not abusing that power. This demands a high level of personal integrity. Unfortunately the dominant culture within large bureaucracies can make it very difficult for individual professionals to work in that way.

## 2.2 NON-DISABLED CHILDREN

The brothers and sisters of disabled children and young people are almost always left out of the equation when it comes to looking at the family experience of living with impairment and disablement. And yet they have a unique and immensely valuable perspective.



Brothers and sisters usually know each other really well and are able to put forward a different view to the parental perspective. This view will often be more apposite with respect to thinking about the relevance of age on aspirations and experience.

The way in which a disabled child is viewed - both within and outside of the family - inevitably affects the way in which brothers and sisters view their experience. When parents hold a positive view of the disabled child, it is highly likely that brothers and sisters will accept that as the status quo and grow up with a healthy loving relationship with their disabled brother or sister.

**However, a negative parental view will usually produce the opposite effect and leave the disabled child more isolated within their family unit:**

*It was the twins sixth birthday party. We didn't have a party for J (disabled twin) as it wouldn't have meant anything to him. We did have a party for R (non disabled twin) though. He invited his friends round. None of them knew he was a twin, none of them knew he had a disabled brother. I think it was a shock for them.*

**Having a positive view, however, will put the non-disabled brother or sister at odds with the predominant view of the world:**

*My daughter always wanted her brother to go to the same school as she went to. When she was little she watched her friends looking out for their little brothers at break time and she wanted to do the same. It was the same at Secondary School. She wanted her brother to go, and she and her friends wanted to support him at dinner time. However, I was advised against this as an option. Our educational psychologist told me it would have a negative effect on my daughter. We did try it for a while and it was unsuccessful as they didn't understand his support needs. Although she understood why we were doing it, my daughter was bitterly disappointed when we took the decision to take him out.*

Either way, siblings find themselves in the middle of complex practical and emotional circumstances within and outside the family. **Family Leadership can only be attained if all members of the family are given a voice.** Putting brothers and sisters in the mix, alongside their disabled sibling and their parents, allows for true Family Leadership.

### 3. FAMILY LEADERSHIP AND PERSONALISED TRANSITION

While Family Leadership is something to strive for from the earliest possible stages, transition is a time when it comes into its own. The fundamental principle on which Personalised Transition is based is that young disabled people and their families have the authority to plan for life after school - with as much support as needed, but no more than is necessary. Families are the rightful foundation for planning and developing the education and support that young people need as they take on adult lives since they are the experts in knowing what they need to make things work for them.

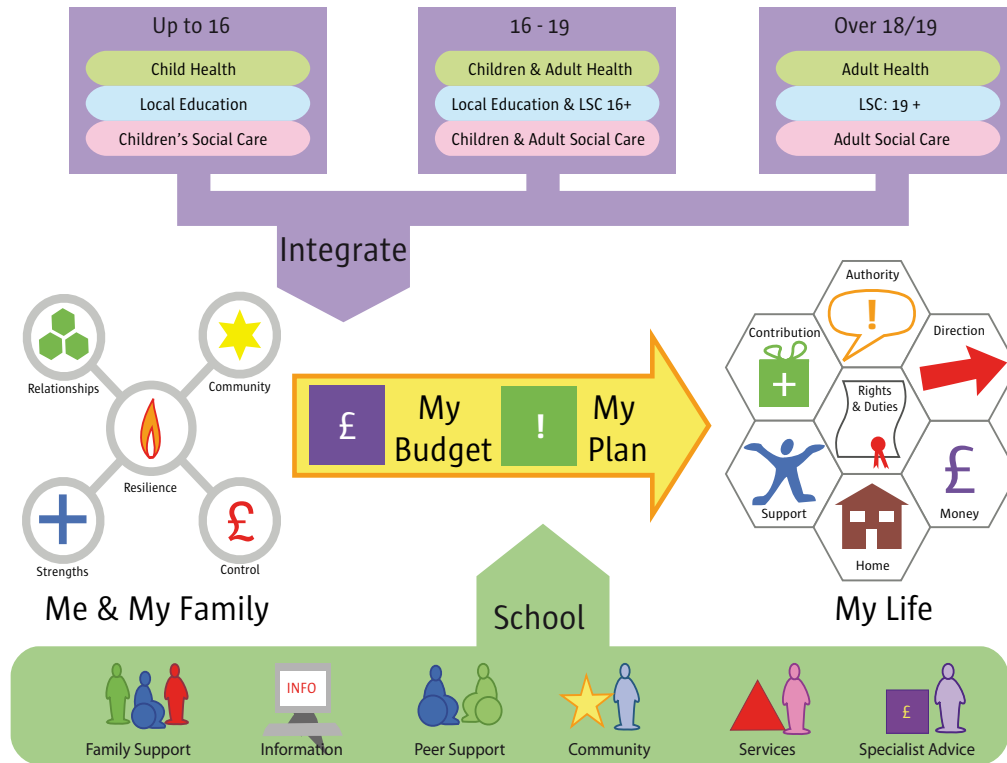
The young person, with the support of their family, has the right to be in control of their own life and to make their own decisions. It is important that the whole process of transition respects and strengthens young people in the exercise of this basic human right.

The essence of the model of Personalised Transition, developing across the Yorkshire and Humber region, is that young people and their families lead the way (see Figure 2). From the late 1990s central government policy and best practice guidelines have recommended that the voices of disabled children, young people and their families should lie at the heart of the way support is developed and shaped.

However, the reality is that young people and parents are frequently marginalised in processes surrounding transition; lack the information they need to make informed decisions; and are absent from the decision making processes with respect to commissioning and shaping services. It is not, therefore, surprising that families continue to report a sense of alienation, disappointment, struggle and disempowerment.

Developing genuine Family Leadership means overcoming the paternalistic culture that is dominant in services for disabled children, young people and their families by offering instead appropriate information and support, whilst making sure that young people and families have

opportunities to work together to realise positive futures. It depends on the relationship between the young person, family and professionals being in equilibrium.



**Figure 2. Personalised Transition**

Currently, most Family Leadership comes in spite of scarce resources and little active encouragement from services. However, the York Carers Strategy manager acknowledged publicly in a recent meeting (DH - Carers and Personalisation) that some people's lives have been transformed because their families have been involved in supporting them with personal budgets, and that this is something that should be listened to, acknowledged and positively encouraged. **Families who can demonstrate leadership will inspire others.**

## 4. DEVELOPING FAMILY LEADERSHIP

There are two sides to Family Leadership:

1. Individual - where families feel motivated, inspired and confident enough to take control of their own lives and make decisions based on their best judgement about what is needed at any point in time
2. Collective - where families are given the resources to help other families; and to feed into local and national strategic direction and commissioning processes

These two sides can only come into view if the contribution that disabled children, young people and their families bring to the world is recognised and nurtured.

**Families tell us their ability to take leadership depends on getting support through 5 distinct dimensions:**

1. Positivity & a can-do approach - championing the voice and independence of young people
2. Peer support & positive role models - being connected to one another
3. Information - knowing about entitlements, services and support available
4. Simplified administration systems - affording genuine choice and control
5. Influencing strategy & commissioning - the collective voice of young people and families being used to inform strategic developments and systemic change

Many of these 5 dimensions of support are now taking on real life within the Yorkshire & Humber region. However there is an urgent need for their further development. There is also a need for local authorities, schools, the NHS and agencies in the voluntary sector to pay attention to all five dimensions. Less than five out of five will not generate genuine family leadership.

### 4.1 POSITIVITY AND A CAN-DO APPROACH

Families need to be encouraged to say what they want to happen, regardless of the availability of activities, support or services. Young people need opportunities to gain the confidence they require to get their preferences and views across. Raising aspirations of young people, parents and professionals lies at the heart of Family Leadership. Schools are ideally placed to challenge the prevailing cultural view that disabled young people are 'less than' by delivering a relevant and meaningful education that builds on young people's natural interests, gifts and skills.

In order to improve outcomes for young people when they leave school, Kelford School in Rotherham is transforming the content of the curriculum and the way that school is organised.

**In order to drive the change forward, staff are focusing attention on some fundamental questions about the purpose of education:**

- What are we educating our children for?
- Is it for a life in a day centre?
- A life on benefits?
- Would it not be better to equip our students for meaningful lives as adults?
- What does a meaningful life mean for each of our students?

Listening to students, however they communicate, is the starting point for designing a relevant, meaningful education for each individual. The organisation and structure of the school is changing accordingly. Their work is in its early stages, but it is already improving experiences and outcomes.

For example, staff are working with family members and colleagues in health and social care to develop a holistic package of education and support to a 17 year-old who has struggled to participate in school life. School will co-ordinate funding streams, manage and train staff and provide an education at home and in the community. Relationships between the young man, his family and school are already greatly improved and the future looks brighter. As the entire school moves to a different way of working the leadership team is expecting such individualised packages to become the norm.

The Blueberry Academy in York is similarly raising aspirations through its work with Applefields School. The Academy is working closely with school and local employers to develop work experience opportunities where

young people can be involved in varied tasks within more than one work placement. This gives young people a breadth of experience that helps them make more informed decisions. Young people are supported in their various work experiences by a job coach. This has been so successful that the model is being sustained for some students when they leave school. Support for work experience will become even more achievable when Access to Work funding or an individual budget from health or social care are used.

In order to help Applefields embed the work so that it becomes their everyday way of doing things, Blueberry Academy has supported staff to make links with the local Jobcentre Plus office and the Disability Employment Adviser. This has been in the form of a group session in school to share information on Jobcentre services and welfare benefits. Students and staff from Applefields have also visited their local Jobcentre. This has helped develop the experience, knowledge and aspirations of young people and the staff who support them within education. It has also helped the Jobcentre to understand the needs of a group whom they have struggled to support.

When schools take the lead in raising aspirations and making things happen for their students, it raises the expectations of parents. As parents plan for their son or daughter to leave school, outcomes can be transformed as we shift from planning around what is available towards planning based on the interests and preferences of the young person.

When we focus on the things that motivate and inspire individual young people then we stop being dependent on others for a 'place' in this service or that resource. Rather we look for a way of fulfilling those interests and focus on the support needed to allow the young person to take part in activities of their choice. In doing this, we help the young person to take control, practice their autonomy and build their self-esteem. This lays the ground for nurturing their inner resilience.

## **4.2 PEER SUPPORT AND POSITIVE ROLE MODELS**

Families of disabled children are frequently isolated from other people going through similar experiences. It is much more difficult for parents of disabled children to make the natural connections that other parents make - for they are largely denied the school gate experience and often live in different neighbourhoods. Making connections, sharing experiences and having access to

resources can help families feel better and grow stronger. Bringing families together in a positive can-do environment is central to the development of Family Leadership.

**As one parent recently reported at the end of some parent-led workshops in Calderdale:**

*It's almost like being given permission to do what you thought you were capable of all along. Affirming!*

**Parent, 2011**

Parents tell us that it is often when they get together with other families that they begin to understand they don't have to accept what is on offer, but they can shape a positive future based around their child's interests and needs.

Lives Unlimited (York) recently held a workshop for disabled young adults, their families, friends and Personal Assistants (PAs) to explore what being a good PA means; gain confidence about becoming an employer; explore aspects of being a good employer, a good PA etc. The day was a resounding success leaving young people, parents and PAs new to the concept of individual budgets and personalisation confident and excited about taking control of their own destinies. And those families already using individual budgets were rewarded for telling their stories through some unexpected consequences of the day: one PA offered to take over the management of the rotas and payroll (he had not realised how much work this was for the parents) and another offered to co-ordinate social outings for a small group of young people (plus PAs) with similar interests.

**Comments at the end of the day included:**

*Chance to meet others and go to a night club.*

**Disabled Young Person**

*I just wanted to say 'thank you' to you (Lives Unlimited) and Pippa and everyone who spoke and organised Saturday's conference. We thoroughly enjoyed meeting everyone. Speaking to current PAs as well as young people and parents was very beneficial to both of us. We came away feeling very positive about my son's future.*

**Parent**

*As a PA I have become more aware of what it is families find most important and how I can make a difference.*

**Personal Assistant**



Calderdale Parent and Carer's Council has been commissioned by their Local Authority to take the lead in planning with families who are receiving support via an individual budget. This is called the *Taking the Lead* project. Bringing families together is central to *Taking the Lead*. The project is supporting a young people's group to develop skills around person centred thinking and planning. In addition to thinking about their own lives, the young people would like to develop Family Leadership by becoming trainers and mentors for other young people. *Taking the Lead* is also giving parent members of the Parent and Carer's Council the skills and confidence to facilitate plans with families. Fifteen parents have attended a four day parent-led course and are now being mentored by a parent to develop their skills around person centred tools, including support planning.

**Reports from parents have been unashamedly enthusiastic. Professionals listening to families present their plans at the end of the project were moved to tears as they listened to each family talk about the impact this modest project has had on their lives:**

*The project has been amazing! I feel like a different person and see my daughter in a completely different way. It has brought us together as a family. I feel like we are starting over again - a kind of re-birth for the whole family. When we started I was full of fear about the future. I still feel anxious and scared, but I am excited too.*

**Parent, 2011**

All families involved in the project have similar stories to tell. And all families are spending their individual budget (made up of money from health, education and social care) in imaginative ways that support the young person to develop their interests and skills.

Such work needs to be developed and encouraged to grow if we are to see more families and communities benefit. Family Leadership is not a 'one off' event, it involves on going work that will not happen without adequate resources.

## 4.3 INFORMATION

Having accurate, timely information about entitlement, process and available options is key to the development of successful Family Leadership. Lacking information about what needs to happen, who is involved and when key tasks need to happen by leaves young people and their families weak, vulnerable, frustrated and unable to take a leadership role. Knowledge is associated with power and clear processes enable people to think for themselves. When families



have an understanding of the world their children are entering into, they can influence, demand and offer constructive criticism with confidence.

*Knowledge is power! Without access to information things won't get better.*

Parent, 2011

Effective plans can only be made on the basis of accurate, up to date information about leisure and social opportunities, micro-enterprises, benefits, housing, employment, volunteering, support services and further education courses etc. Compiling information about the range of support and activities young people and families might find helpful and enjoy helps families make choices. Placing information about community resources alongside traditional services helps everyone think beyond traditional support and come up with new ideas. An information directory also exposes gaps in activities and support that allows providers, commissioners and families to develop new initiatives.

School is ideally situated to host workshops for parents on basic rights to benefits, legal status post 16, looking at college etc. Such workshops not only provide valuable information but also give parents opportunities to get to know one another.

To give families the best chance to shape meaningful adult lives for their sons and daughters Talbot School, Sheffield compiled a folder of leaflets and flyers giving families information and costs about some of the provider agencies in the city. Families used these folders as an aid to making plans for their son or daughter when leaving school.

Information markets giving families opportunities to meet providers, talk about the support they offer and find out what is available are welcomed by parents. Many local authorities, including City of York Council, Barnsley MBC and NE Lincs Council run Opportunity Fairs or Futures Markets for children and young people with SEN. Typically local and regional providers attend these events offering stands and workshops to promote their services.

Hearing success stories from other families is the most effective way of spreading enthusiasm for the uptake of individual budgets. The York Forum for Parents of Disabled Children is using part of the government Aiming High for Disabled Children grant for participation of parents, to run a conference about transition. The *How to Have a Good Life* conference is for families of disabled children and young people living in the York region.

The day aims to show what is possible by looking at what young people can do and using examples from other families about the effect that creative and flexible thinking can have on everyone's lives. The day is about helping families move away from having to 'fit in' to existing services to celebrating

individual dreams. Stories from families who can and have made it happen will take centre stage. Workshops include support planning, writing information about your child or young person, parent input in annual reviews, and having confidence in meetings about your child.

### 4.4 SIMPLIFIED ADMINISTRATION SYSTEMS

Families need to be given clear and transparent information around entitlements to support from health, social care and education (e.g. entitlement to a community care assessment, learning up to the age of 25 and support from continuing health care). At present entitlements in all these areas are weak and information about what entitlements there are is almost non-existent.

**For example, many families are unaware that someone with learning difficulties is entitled to have a community care assessment but has no entitlement to have their basic support needs met, or that many local authorities impose a top limit on the amount of money anyone can receive, regardless of their needs.**

*My son has high support needs. He has always needed, and will always need 1-1 support for all his waking hours. He also needs someone to be able to keep an eye on him if he gets up in the night. He can and does get himself into dangerous situations very easily. Max would like to live on his own, and I would like him to move out of the family home. It is the right time. We put all this in his assessment, but the amount of money he has been given does not cover him 24/7. He can't possibly move out on the budget he has been given. We have queried this, but have been told he is on the maximum amount anyone gets. If that is true it is discrimination - it means that just because he has high support needs he cannot live on his own as he will never have enough money to cover his needs.*

**Parent, 2010**

Stories similar to the one above are rife throughout the region. Families who go through such an experience are left feeling the promises of personalisation are at odds with their actual experience. This breeds greater mistrust and cynicism, and makes other parents wary of self-directed support.

As the quote above illustrates, families report that the process of getting an individual budget can be cumbersome and confusing. In order that

young people and families have genuine choice and control around support, administrative and planning systems have to be designed around them.

- Assessments need to be streamlined as much as possible, with agencies working closely together to reduce complexity and confusion.
- Dates and timelines need to be co-ordinated between agencies; families need to have adequate time to plan and put support in place well before the date for leaving school.
- The content of support plans needs to be as simple as possible with families given clear guidelines as to the purpose of the plan and the systems in place to have the plan agreed and reviewed.

**If personalisation is to succeed, professionals need to move beyond fine rhetoric and demonstrate through their actions that they genuinely believe families know best what they need and trust them to do the best for their son or daughter:**

*It's all about trust. I said to one of our senior managers 'You have to trust us now! This cannot work unless you trust us'.*

Parent Development Worker, 2011

In all areas of the region, it seems that the most imaginative use of individual budgets happens if young people are supported by their families. However, it is rare for statutory agencies to fund such initiatives. Lives Unlimited (York) works to inspire other families about individual budgets and puts on events for disabled people and families that demonstrate what's possible in terms of family supported independent living.

Recent and forthcoming examples are events about circles of support, person centred reviews, training PAs, support planning and getting a great life using an individual budget. The work of Lives Unlimited is restricted as it does not receive funding from children's or adult services. Almost all of its work is done on an unpaid basis, with modest amounts of funding to host inspiration days coming through grants.

## 4.5 INFLUENCING STRATEGY AND COMMISSIONING

As we looked for examples of the five aspects of family leadership it became obvious that this final feature is the least explored. The fact that this is so gives an indication of why the other four features

are sparsely spread across the region. As long as families are denied opportunities to influence strategic development and systemic change, their opportunities for leadership remain at best destined to a campaigning role from the margins and at worst frustrated by lost opportunities.

It seems amazing to consider that authorities can develop services for people without having those people on board. It's almost like this area is too precious for anyone else to work on.

*I think that it's just not happened before - 'power' being handed over to someone who isn't paid to do something. But I think it's more to do with being open and honest and saying "you lead this, just tell us what you want us to do". That's a big leap of faith.*

Alison Cowen and Jo Whitehead, Parents, 2011

**If individual young people and their families are to be at the centre of planning for their future, the collective voice of young people and their families has to inform strategic planning and systemic change:**

*Parents need to be active members of planning teams. That is: not just commenting on decisions that have already been made but being given equal status and say in generating plans for service development right from the start.*

Katie Clarke, Parent Development Worker, 2010

Professionals working with families need to feed information from young people and families up to senior managers and commissioners in both children's and adult services.

Calderdale Parent and Carers Council works closely with commissioners from Health and Children's Services and co-ordinates regular meetings to ensure that messages from parents are fed into strategic decision-making forums. In York, parents are members of a strategic group - *Moving into Adult Life*. Here, senior managers from health, education and social services oversee developments through the Transition phase. A consultation led by a parent for the Local Authority has formed the basis of developments and work by teams over the last two years.

The recent endorsement of a Partnership Charter, by the Director of Adults, Children and Education in York, indicates a commitment to listening to the voice of parents and working together. However, for this to be meaningful then real power will need to move from the state to families.

## 5. FINANCIAL IMPLICATIONS

This paper argues that Family Leadership is essential if we are to support families in way that increases their natural resilience. However, we also argue that Family Leadership will not progress unless it is adequately resourced. Some parents may develop things locally for short periods of time but unless they have the support of statutory agencies such initiatives will inevitably be unsustainable.

We are facing a period of financial cutbacks and so it is likely that this call for funding will be hard to hear. To make this easier, we are going to look at what can happen when Family Leadership is given a modest amount of financial support.

**Calderdale Parent and Carer's Council (CPCC) was given £20,000 to take the lead on working with children, young people and families to introduce Individual Budgets. Their work consisted of four strands:**

- 1. Strategic Leadership** - co-ordinating meetings between all agencies, ensuring key stakeholders were involved and feeding findings from the project to appropriate strategic groups across.
- 2. Working with young people** - the 'Taking the Lead' group of young people acted as a steering group throughout the project. This group is now looking for funding so that it can continue to develop young leaders. They intend to carry on working together to ensure that the young people can continue to develop skills to support them into employment. They have done their own PATH which includes wanting to talk to government, making a training DVD on personal assistants and working together in schools as mentors for young people.
- 3. Training parents** - Three external (parent) trainers were brought in to give parents the skills they need to think and plan in a holistic, family-friendly way. Fifteen parents took part and five of them worked closely with the five families embarking on an Individual Budget. These parent planners will continue to support the families for another six months by acting as facilitator for their circle of support.
- 4. Support planning and panel meeting** - CPCC arranged for families to come together to start work on their plans for how their allocated money would be spent. Each family had a facilitator who stayed in touch with them after the day to help them complete their planning. The facilitators were supported by an external parent mentor who

was available to visit and at the end of the phone. Six weeks after the support planning day, CPCC co-ordinated a panel meeting with representatives from health and social care to approve the plans the families had created. Each of the five families presented their plan to the panel.

As CPCC worked with families around planning, social workers carried out the necessary assessments and informed families about their budgets. As the six month project comes to an end, there are several features that deserve a mention:

- Families were supported by parents and this enabled them to take steps they would not previously have considered taking. At every step of the way, families had another parent at the end of the phone or someone to visit them at home. In turn, each of the supporting parents had a mentor at the end of their phone. The love and energy propelling the project meant that everyone went the extra mile.
- Senior managers in health and social care trusted the Parent and Carer's Council to deliver. They are now extremely pleased and understandably proud of the results they have achieved. With the backing of the Local Authority, the Parent and Carer's Council succeeded in bringing key players together and breaking down systemic barriers previously resistant to change.
- The work took place in a short period of time - the project lasted for six months and in that time, families new to the concept of individual budgets came to understand the advantages that they can they bring.
- Some families have integrated budgets from health, social care and education.
- The work has produced a lasting legacy throughout Calderdale - the young people's group is looking for further funding to continue; parents are continuing with their programmes of training and mentoring; families receiving support are fully engaged and will contribute to the ongoing development of work in Calderdale by feeding back what is working, and what needs to improve; families are connected to each other and so have an informal network of support; and professionals have been moved by the impact of the work and see that this approach can make a difference.

Since this work with families accessing individual budgets has got underway, CPCC have successfully raised funding for 8 more PATHS which will be done by their team of parent planners, who will all be paid on an hourly rate on contract with the Parent Council. The Parent Council have worked out a cost for a PATH and a support plan and will begin to cover some of the costs incurred through planning and supporting families.



The initial work in Calderdale involved 5 families receiving individual budgets; a further 15 parents were involved in training and mentoring; 5 young adults formed the young people's group; and approximately 20 professionals. It is impossible at this stage to estimate the long term benefits - strength, resilience, connections made in local communities etc - that will almost certainly lead to greater long-term savings. In the short term the benefits include more confident families; professionals with a greater understanding of the benefits true personalisation brings; improved interagency working; a small number of parents taking up occasional paid employment as support planning facilitators; and happier young people.

It is hard to make a straight comparison with the costs of traditional support for families partly because costs are hard to come across, and also because the outcomes between a personalised and a traditional approach are so different. On top of this the actual outcomes - i.e. the practical differences an intervention makes to the quality of life - is hard to quantify.

The cost of the Calderdale project (£20,000) can only be compared to the costs of traditional assessment, planning and outcomes. Research by Loughborough University found that the total average cost for assessment, planning and review over a six month period for children with emotional or behavioural difficulties comes to £1,494. That amount comes down to £905 per six months for a Child in Need with no additional need type (Holmes et al, 2010).

In Calderdale social workers carried out the initial assessment, but CPCC did all the support planning, panel meeting and will review the packages. A rough estimate of the direct spend on the 5 families taking part would be £10,000. This breaks down to £2,000 for each family. However breaking the spend down in this way ignores the 15 parents now trained to support families plan for their individual budget or the workforce development training which happened as a matter of course. Most importantly breaking the money down in this way ignores the capacity being built up locally as parents throughout Calderdale develop skills and confidence to support each other come up with creative solutions to the difficulties they face.

Real financial savings begin to emerge when we examine how money is used. For example, a traditional support service like residential respite care costs £266 per night (McDermid, 2010). However none of the Calderdale families chose this expensive option; all of them preferring to employ Personal Assistants at a rate of approximately £10 an hour (including on-costs). Similarly we will significant savings when people move away from traditional day centres that costs £130.99 per day (ibid).

**Although it is impossible to give accurate figures to the amount of money needed, the evidence we have so far indicates that the preparation, assessment and planning processes cost much the same as they presently**

**do.** Yet importantly, the outcomes of the processes used by the Calderdale parents were empowering and helped parents become more resilient. This is the opposite to a traditional approach which, as we outlined at the beginning of this article, disempowers families and increases their dependency on the state.



## 6. FINAL THOUGHTS

Family Leadership lies at the heart of Personalised Transition, yet organisational systems and cultural beliefs make it incredibly hard for Family Leadership to grow and flourish. We are extremely fortunate that we have strong, visionary families and parent-led organisations across the region who are working hard to take this agenda forward.

**Family Leadership requires a change in the way we think and behave:**

- It depends on professionals, at all levels, trusting that families are doing the best they can for their children, just as they do the best they can in their job.
- It demands that parents realise their potential as active participants in shaping the support they receive rather than being a passive recipient.
- It depends on taking a whole view of the family, rather than putting different issues into discrete compartments.

**Above all, Family Leadership demands that we all respect disabled young people and find ways to help them express and realise their dreams.**

In the short term, developing Family Leadership costs no more than doing things traditionally but produces improved outcomes and is a rewarding experience for everyone involved. In the long term we anticipate that Family Leadership will bring more benefits as families and communities become more autonomous and self-sufficient as they realise its power.

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# ORGANISATIONS

## Calderdale Parent and Carer's Council (CPCC)

CPCC was established over 10 years ago and has a national reputation as a good model for parent participation. One of the members of staff is a regional representative on the National Network of Parent Carer Forums Task Group. They also influence strategically at local, regional and national level.

CPCC currently employs 5 members of staff (3 of whom are parents) and is growing to include parent volunteers and parents paid to support the work on a sessional basis.

CPCC reaches around 500 families across Calderdale. They offer peer support over the phone and are now setting up a Face 2 Face scheme with a volunteer co-ordinator. They run regular events across the locality offering families the opportunity to come together, network, share information and support. CPCC has a training team of parents who train professionals and who have developed their own course based on their individual stories.

CPCC holds information sessions, training for families, and develops projects and services around the needs of local families. They work in partnership with many local voluntary and community organisations, and the public sector to support families to create positive change in their daily lives. They work alongside families in a positive solution-focused way offering signposting, information, newsletters and a website.

[www.parents-and-carers.org.uk](http://www.parents-and-carers.org.uk)

### Children And Inclusion (CANDI) (York)

CANDI is a parent council. The group has been running around 3 years and currently has no staff but has been granted a small amount of funding from City of York Council for the participation of parents in service development. They have around 80 members and run a volunteer parent telephone Listening Service.

Primarily their work focuses on promoting inclusive attitudes and practice, and challenging discrimination. By developing partnership working and family leadership, there is a form of social support that is more active and distinct from more traditional support groups. They meet at least once every half term and are developing training for parents as well as for the professionals who work with their children. CANDI have co-written and help to deliver Disability Equality training directly to groups and service teams involved with disabled children.

Parents of disabled children represent CANDI at strategic group meetings with the Local Authority, to give a parent's view about how education, health and social services should be developed.

Parents are directly involved in the development of CANDI through an active Committee which gives the group direction and makes sure things get done. The action plan, which is refreshed every year, is drawn up using ideas from all members. Most of all parents involved in CANDI are ordinary people who want to share their experience of family life with other parents.

[www.yorcandi.org.uk](http://www.yorcandi.org.uk)

### Lives Unlimited (York)

Lives Unlimited is a family and user led group of people, all volunteers, who are actively working towards enabling disabled people and older people in the York area to:

- Have more control over their lives
- Be included as equal citizens
- Enjoy the same choices and opportunities as anyone else in their communities

Lives Unlimited are a group of family members who have done support planning with a son or daughter or other relative who are now enjoying active and fulfilling lives using a personal budget. Lives Unlimited are helping develop support planning for families in York. They are happy to:

- Share their own experiences
- Work alongside other families
- Share their thinking about what they want for their future and how to achieve it
- Share their experiences of staying in control of the plan and passing on the information they have found useful

Lives Unlimited members have experience of:

- Planning with their own sons and daughters to think about what they wanted to do with their lives
- Thinking about the outcomes they wanted from the Plan and putting the plans into action
- Independent living
- Finding resources to meet what people want to do
- Recruiting and employing personal assistants (PAs)
- Training and supervising PAs
- Running training workshops and information events

Members of Lives Unlimited are already involved in other family leadership initiatives such as Partners in Policymaking, Kindred Spirits and All Together Better. Two members are members of the Learning Disability Partnership Board. These parents have enormous expertise and an unwavering commitment to making things better for other families. Modest investment from health and social care would undoubtedly lead to financial savings and the growth of trust and resilience.

[www.livesunlimited.org.uk](http://www.livesunlimited.org.uk)

### The Blueberry Academy

The Blueberry Academy works across the region to support disabled young people to find out what they want kind of paid employment they would like to do and creates opportunities for them to learn the skills they need to fulfill their dreams. The Academy supports education and advice providers to improve how they support young people to prepare for and enter employment and helps to implement the Getting a Life model - improving culture, aspirations and achievement for young people.

[www.blueberryacademy.co.uk](http://www.blueberryacademy.co.uk)

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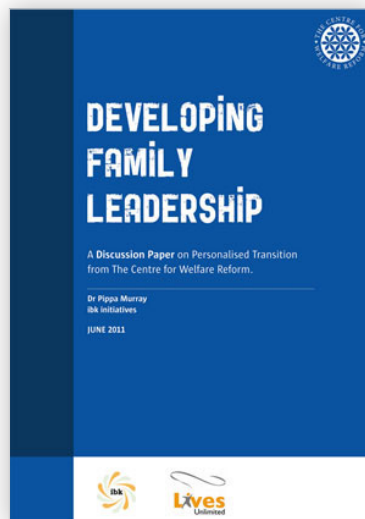
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