

Ali's story

in Control is grateful to Ali for sharing this story

Ali is 16 and lives in the northwest of England. Ali is a lovely young woman who lives with her loving parents and brothers

A story about how Ali was able to get a Personal Budget combining Health and Social Services funding.

▶ 1 2 3...

In this story each number represents a catalyst – a trigger to further action.

▶ 1

Ali's family contacted the North West Training and Development Team Lead on Health through a 'Partners in Policy making' graduate in 2004. At that time Ali was fourteen and a half. Even though they had the support of services, Ali and her family were approaching Ali's move into adult life with some trepidation.

▶ 2

At that time Ali's family felt exhausted, stressed and let down by Health and Social Services. They were anticipating a developing crisis; Ali's foster mother was planning to retire, the 'respite' services offered by the local authority were unsuitable and unacceptable to Ali and her family and the local Social Services Children's Department were struggling to find any suitable alternatives.

▶ 3

Planning and support from services was hampered by an absence of community based health services for children and young people with disabilities. This was especially relevant and important

Story Ali

to Ali as she has complex and continuing health needs with some dependence on medical technology.

▶ 4

Local health and social care services acknowledged that there was no community based service for disabled children. Work was beginning to address the situation but to date this has not been resolved.

Ali's family says **“We have sat around at meetings with lots of professionals for more than fourteen years, at the end of the meetings everyone goes home and nothing changes. All we want is simple things like someone to come and do the ironing so we can get on with caring for Ali”**

▶ 5

The first step was to develop a relationship and listen to the family's story. This was done over a number of weeks - occasionally over a bottle of wine - at the family home on a Saturday evening. Lots of information came from these 'informal' discussions and the family started to explore possibilities. **It is important to note here that at the end of about six weeks nothing had changed in relation to services but everything had changed in relation to the family's perception of what was possible.**

▶ 6

Initially Ali's family was asking for options that had already been offered by local services i.e. more 'respite' and a replacement 'foster mother'. These were the only options on offer. Direct payments had been mentioned but mum was adamant that taking on extra responsibility at this point was not possible.

The 'respite' services offered were managed by the Local Authority and straight away big concerns arose over staff competency and clinical skills in relation to caring for Ali. Social Services were actively seeking an alternative foster mum for the family. However, time was getting short. Only eighteen months remained before the foster mum who had been caring for Ali for fourteen years retired. The family became more and more panicky and doubtful about finding an alternative.

Story Ali

Once Ali's family had been able to talk about their experiences with services we began to explore alternatives - what would the family want if there were no constraints?

▶ 7

The next step was to talk to services. An initial meeting was set up at the family home with those considered to be critical to facilitate change: the lead for disabled children in Social Services in the County, the Social Services manager for that district, the social worker & representatives of services already involved.

Ali's family says "We didn't think for a minute that they would come to our house!"

Unfortunately the local Primary Care Trust Commissioner for disabled children's health services was unavailable but this was resolved at a later date.

The outcome of the meeting was to create a common understanding and an agreement to see what developed and to assist with the process if possible.

▶ 8

The starting point was to start to develop a person-centred plan around Ali. For this we asked for expertise from local adult services. The person-centred planning lead came along to help the family develop Ali's plan; This was the first time the family felt they had been central to any planning process around Ali and also the first time that they had been encouraged to express their dreams, hopes and aspirations for the future.

The person-centred plan took several months to complete. The importance of this process lay more in the learning along the way than just in the end product.

At the end of the process the family had developed a plan, identified support needed and worked out the costs at approximately £60k per year.

Ali's family says "**We feel like we had been taken to a shop and shown two or three items to choose from, when in the backroom were shelves of options that we hadn't been shown!**"

The plan arrived at by the family involved taking control by means of an 'individualised' budget. This budget would be used by the family to hire their own wrap-around staff team for Ali.

Story Ali

At this point education were not involved as the family felt this support was stable and they didn't want to upset this aspect of Ali's support system. The individualised budget will be used alongside the foster mum until the support package is fully developed and the family are confident enough to leave behind additional supports.

► 9

Negotiations began with the Local Authority and PCT about funding. Ali's mum started to develop her own expertise and confidence by first accepting just a small amount of direct payment money (16 hours support). She began to develop a relationship with the local disability federation who acted as brokers in relation to the direct payments.

The Primary Care Trust (PCT) Commissioner received a copy of Ali's detailed person-centred plan and agreed to come and meet Ali and her family to reconsider her situation. Previously Ali had been turned down for health funding as the complexity of need had not been communicated adequately. The result was an agreement in principle to use shared funding for any future support package, providing a mechanism could be found that would facilitate the movement of funding from the PCT into an individualised support system.

Research was done about possible ways of releasing health care monies to local authorities which would then be able to pay out the monies as a direct payment into a personal trust bank account set up on behalf of Ali.

The solution agreed was to transfer money under section 28a of the NHS Community Care Act 1999 (£27k Social Services + £30k PCT).

► 10

The first monthly payment went into Ali's bank account in December 05.

Ali's mum says **“Never in my wildest dreams did I imagine that this would ever be possible”**.

The local disability federation agreed to assist with practicalities such as job descriptions and checking out legalities etc. The family was still learning as the process developed and contact

Story Ali

between the NWTDT health lead and the family continued. However, they steadily became confident enough to navigate and negotiate with only occasional assistance and advice.

Ali's mum says: **“Most people would agree that it's not an ideal situation having to have people from outside of the family to come into your home on a regular basis to offer help. The beauty of an Individualised Budget, however, has meant that each of the four P.A's we employ has been hand-picked by ourselves to ensure we get the right people for the job, people we can trust and feel comfortable around. They bring with them a range of skills, interests and personalities and Ali enjoys having these new friends in her life to help her become more independent of her parents. Her social life has taken on a new dimension. We can even take P.A's away on holiday to share the responsibility, ensuring that everyone comes back feeling that they've actually had a holiday!”**

Having the help in our own home, has meant we can still do all the things we've always done for Ali when we want to, but the difference is that now we're not obliged to, we have a choice. Our time can be shared more evenly between our three children, and her Dad and I are experiencing some of the freedom other parents of teenagers start to reclaim and take for granted.

I'd be lying if I said it was all plain sailing, because it isn't. There are always bound to be a few hiccups along the way, but that applies to all walks of life. In my opinion this has got to be the best option out there for families caring for a disabled person, who are looking for some respite in their own home but want to remain in control of the situation themselves”.

Further thoughts about the catalysts to change – the things that made it all happen....



Ali's family made contact via a Partners in Policy Making Graduates not through services. Local services have invested into leadership development and strong family networks via Partners in Policy making.

For Partners in Policy making information, contact Lynne Elwell lynne.elwell@yahoo.co.uk

Story Ali

▶ 2

A looming crisis brought the situation to a head. The downside of this meant that Ali's family was stressed before work started and it took several weeks listening to get to a position where the family started to feel that they could regain control of the situation and start to plan for the future.

Services often look for readymade solutions within existing structures rather than develop the skills and expertise of staff to work with families so that they can develop their own solutions. This is skilled and long term work which is often hampered by service structures, insensitivity of staff and the divide between health, social care and education.

A sensible investment in small scale pilots that look at competency development across staff as well as structures may be useful.

▶ 3

A gap in local services - no community based team for disabled children - meant that Ali's family were unable to access professional health support in a number of areas and didn't have a health professional taking overall responsibility for assessing and negotiating the health care package. Health staff felt as powerless as the family in the situation, each service only taking responsibility for its own sphere of responsibility. Everyone was a loser because failing to meet Ali's overall health needs was leading to emergency situations, and these resulted in unnecessary hospital admissions. There was also an effect on the health and well being of the rest of the family.

Health services stand to gain much from acknowledging and harnessing the skill, expertise, ability and creativity within families to manage complex support packages. A small investment of health care monies into families who are caring for children and young people with complex and continuing health care needs, some of whom are dependant on medical technology, can lead to benefits in both human and financial terms - a win / win situation for all involved.

Story Ali**▶ 4**

Ali's family needed to be able to trust services again. Much damage had been done to the family's confidence in services. A number of factors contributed to this loss of confidence – for example, the family didn't feel they had much power or control over decisions taken within services about their own daughter.

▶ 5

Ali's family was asking for solutions that services could offer because no other options had been explored.

Service workers need to shift their thinking away from providing off-the-shelf solutions and towards empowering families and enabling people to work out their own family and person centred solutions.

▶ 6

Navigating services and identifying key personnel is important – families get exhausted trying to initiate change with people in services who haven't the knowledge or authority to make a difference. This is especially important when several agencies are involved. Bringing people together to work out a way forward and understand each other's constraints can sometimes remove barriers. Good working relationships between staff and agencies are clearly important.

▶ 7

This was the first time that Ali and her family had been exposed to person-centred planning. The process was an important learning curve for everyone. Without going through the process the family had not been able to work out solutions. The involvement of the local person-centred planning lead gave the process credibility within services.

▶ 8

The person-centred plan provided the basis for negotiations with the PCT Commissioner. The biggest obstacle following discussions was not 'proving' health needs because that information

Story Ali

was now captured on paper. The biggest blockage was finding a mechanism for moving Health monies into a personal budget.

▶ 9

Identifying an agency and / or individuals who can provide expertise and support to the family is critical to the success of the support system and the confidence of the family. The family needs to be sufficiently confident to manage new arrangements, especially in the initial phases.

Cost analysis and comparison of options.

There was a very real risk that Ali's family would not have been able to continue to care for Ali at home over the next few years without any change in the support system. If the situation had been allowed to deteriorate then everyone would have lost out.

Ali's social worker had made preliminary enquiries about residential placements. These placements would have been out of district and cost in the region of £170k.

The individualised budget costs £57k.

Mechanism used for moving money from health to SS

£30k was released by the Primary Care Trust to the Local Authority by using Section 28a transfer of monies. This amount was then added to a further £27k made available by Social Services as an individualised budget. The total amount is paid out to the family into Ali's personal trust account in monthly installments. The local disability federation acts as a facilitator in relation to human resource issues and budgeting.