

Me, My Family, My Home, My Friends and My Life

better lives for children, young people and families

2016



Me, My Family, My Home **My Friends and My Life**

Acknowledgements:

To all those who have worked so hard on this project to make a difference a massive thank you: to the whole team at In Control including Sam Sly, Tricia Nicoll, Andrew Tyson and Tim Keilty; to those in local authorities who have owned this project and led from the front; to the NHS PHB/IPC Team for their support; members of the Steering group including Harry Barrow, Simon Cross and Alicia Wood and most importantly to the children, young people and families who have taken part.

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How this report works

This report provides an honest and engaging overview of the last year of work. Integrating support and funding is central to the forward drive of policy, yet there is huge risk that a focus on system and process mean we will miss the opportunity of making significant improvements to the lives of children, young people and their families.

To bring this report to life the web version incorporates many audio files with people involved sharing key thoughts, comments, reflections and thinking. This year of work is about a community of people from six different areas across England, members of In Control, many families, children and young people and national representatives working together to start making a profound difference to the way families, children and young people are supported.



Please listen to what so many people have to say, simply by clicking on the links. You can also download a printable version.



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Summary

IT'S ABOUT PEOPLE'S LIVES, NOT ABOUT PLANS OR SERVICES

- The process of making and agreeing plans, for example Education, Health and Care Plans, and “designing a service” often dominates our thinking in ways that are not always helpful. Fundamentally our work is not about plans or about service design, it's about *doing whatever it takes* to keep children safe and well and about giving families the best possible chance of a good life. Focus on process and systems often mean the real, fundamental things a family require become lost in our wish to help them get a great plan in place.

Jenny, a parent of a young man talks about her experiences on the project.

LISTEN HARD

- Listening to families, children and young people talk about their day-to-day lives, what is important *to* them, and observing carefully what is important *for* them, is absolutely central to this process. We need to hear about their experiences of support in the past and about what kinds of support they believe will work for them going forward. We need to help families to have the confidence to discuss the ‘ins and outs’ of their everyday life without fear of recrimination. Assessment forms can come later.

START WITH THE ORDINARY

- Critically, we need to think about how best to engage the important “non-professionals” in a family's life. Start with the ordinary.
- First base for every planning process must be strengths/ assets/community resources, what we sometimes call ‘natural supports’. Some families will, of course be more isolated than others for all sorts of reasons.

FOR MOST PEOPLE A GOOD LIFE FOLLOWS FROM A GOOD PLAN

- To improve things for children and families with the most complex needs, our experience suggests that we really need to get to know them – and in some shape or form, we do need to help them plan. In doing this we need to pay very close attention to what they are showing us and saying about their lives, and what will make a difference to them.
- Excellent facilitation and good planning, based on person-centred principles make all the difference in the world. When the sceptics see good plans transforming the lives of the most “difficult” families, this is when they sit up and take note – and the light switch goes on.

MAKE THINGS EASY

- Many of the challenges we face derive from the historical way services and access to services, have been developed and delivered. The project has demonstrated a massive weight of bureaucratic complexity, bearing down on families when they come to the state for help and support.
- Overly complex systems are the enemies of effective joined-up working and this is one of the main reasons that today's system fails families. There is a pressing need to do things in ways that are simpler and less baffling for all concerned.

MOST FRONTLINE WORKERS GET IT

- Most staff who work with families are quick to recognise and embrace person-centred thinking and working. In the six Me, My Family My Home project areas, almost all the managers were strong advocates for the approach. It was equally apparent that this buy-in was frequently not shared by others within the council, or by key players in partner agencies. This resulted in a great deal of frustration felt by both families and front line workers who were keen to get on with the project and working in a whole life, whole family way.

ASK FAMILIES TO PLAY THEIR PART

- We need to change the expectations we place on families. The Government has recognised the conflict and adversity in the system with families almost expecting it, becoming accustomed to fighting for every penny or every scrap of service.
- We can point to great examples from the project where workers and families have started a very different conversation. But for it to be sustained system-wide, we need staff who are assertive and strong in delivering the expectation that families must continue to play *their* part in stepping away from conflict with professionals and services; and in doing so, taking responsibility for their life.

MAKE SURE EVERYONE IS ON BOARD

- This change is about a whole-system. This means that the new thinking must apply to *all* who work in that system: social care professionals and managers; GPs, hospitals and specialist health services; schools and other educational services; and we need to engage and inspire others even further afield. A weakness at any point can compromise the whole system and let children and families down.
- Schools and colleges are key partners in setting out a whole life approach; how things are at home impact on a child's ability to learn and participate and vice versa. We have worked with some great educational professionals who have really engaged in the project, however this hasn't been a common experience. Lack of engagement seems to stem from misunderstandings about the project, as soon as the intention of the work has been explained in most cases teachers and educational professionals have engaged much more positively but it remains a challenge and has required some investment of additional time to make this happen. The reality for the project is that happy healthy children and young people will do better at school and schools will be better schools if their pupils arrive as happy and healthy as they can be.

STAND WITH FAMILIES

- At the end of the day, what we are addressing is less a question of the delivery of services or processes (no matter how good), and much more a question of the quality of relationships. This means relationships at all levels, in all directions, between professionals and families, and within and between agencies.



Foreword

Nicola Gitsham, Senior Adviser (Children and Young people) in the NHS England Integrated Personal Commissioning team explains her work, how it draws heavily on much of the base of person centred working in the Me My Family My Home project, and reflects on the challenges we have all encountered in the last year.

Nicola Gitsham discusses the challenges of making this project work and the links with the NHS England Integrated Personal Commissioning programme.

Introduction

Me My Family My Home is ambitious. It seeks to make significant improvements to the lives and support received by children, young people and their families, moving to a single ‘whole life, whole family’ approach.

Tricia Nicoll, In Control explains what ‘whole life, whole family means’.

To be successful the project needed to:

- Challenge long term embedded culture, i.e. ‘the way we do things round here’ and
- Work alongside complex systems and process; including those allied to supporting the new EHC Plans, or similarly complex “Looked After” Children pathways.

Wider pressures should also be noted with the project taking place at a time when:

- Local authorities are challenged to deliver on a large number of conversions from Statements of SEN to EHC Plans, and radically overhaul and improve their support to “Looked After” Children
- When health services are looking to roll out personal health budgets across all those with long term conditions and

- When Local authorities and their partners are managing significant budgetary and resource pressures often losing experienced members of their teams who are best placed to take this work forward.

In the early stages we looked to be working with over 40 children and young people, however, whilst the work with families is ongoing, we have only seen 20 support packages for children and young people with complex support needs and complicated home and family lives go live at the time of writing. This is not though for lack of effort of many people, and much acknowledgement must be made to the many hours of hard work invested.

Josh Hang Gong, Cambridgeshire Children’s Services explains the challenges of taking this project forward over the last year

The major challenge to date has been maintaining the focus on whole life, whole family. We have sought to make best use of local systems and help inform their development, however too often these systems and new approaches have got in the way of the central impetus of this project; to make significant improvements to the support and hence lives of children and their families.

It has proved to be a very rich project in terms of highlighting the need for a fundamental change in approach; centring work around a child and their family, keeping things simple so that all understand, and the 'resistance' within the system to doing things differently.

The real 'nuts and bolts' of this project are 'getting on and doing' and 'making change happen', getting behind the rhetoric of 'person centred-ness' and setting out what this really means:

- Hard work
- Strong leadership;
- Solid Partnerships with families;
- A responsive offer of support; and
- The tenacity of not accepting either the status quo or any barrier as a reason not to work for success.

We have set out a very simple framework, it is not a toolkit or a prescriptive process; there needs to be space within it to accommodate different children in very different situations, it needs to have space for managing crisis, and most importantly it

has to give frontline workers the space to react and work alongside families in a way that makes sense at that moment in time. As explained by the team in Middlesbrough...

'IT'S NOT WHAT YOU DO IT'S THE WAY YOU DO IT'

All sites set out with the intention of this being the first year in transforming their approach to planning and supporting not just those children and families focused on in the project but more widely.

Richard Holland from Cambridgeshire Children's Services explains their plans for the future and how they have used the year of work on Me My Family My Home

At the core is a message to **'Just get on and do it'**. We have all the tools we need, we have children, young people and families in very complicated situations, we have legislation which opens the door widely to allow innovative and creative approaches to supporting people of all ages and we are working in an environment which challenges us all to be more efficient in how we use time and funding. There is no reason not to simply **'get on and do it'**.

The nuts and bolts

The project started with a focus on children and young people with complex support needs and/or complicated home and family lives.

These are the key factors for undertaking this project:

- the ongoing increase in placing children and young people away from home in high cost placements
- the lack of any established approach in any local area to developing appropriate and needed support for children, young people and their families, including the lack of any skills base / workforce able to work in the way outlined in this project
- the need to explore the use of personal budgets as part of whole provision available to invest in families, building resilience, skills and strength
- the national move, through the NHS England Integrated Personal Commissioning programme to integrate support particularly for those with complex support needs and long term conditions
- to support local work on the NHS England Transforming Care Programme reducing the use of out of area placements for children and young people with learning disabilities and autism

We wanted to start back at the beginning by listening to people's life experiences, develop a person centred plan of sorts and then to take forward in partnership with the child and family the development of support which made sense.

We set out to work with between 4 and 6 children and young people and their families in six local authorities (Middlesbrough, Gloucestershire, Greenwich, West Sussex, Cambridgeshire and Leicester). Each site set up its own steering group and worked to identify children and young people and families who may wish to be involved. Each site took their own approach including working with a shared-care setting which had recently been re-commissioned and set out to develop joined-up support across home and the service built on two previous years of work with children and young people in the care system and; another identifying the key crunch points in a child's life (nursery to primary, primary to secondary etc) and recruiting children and young in those age bands.



An In Control Team member worked alongside a group of designated planners in each site. They provided training and mentored them over the year and attended Steering Group meetings as well as supporting individual pieces of work. They offered advice to those involved and worked closely with the families, young people and children and aimed to leave a sustainable capacity of knowledge, skills and people in each area to take the work forward in future years.

The project was overseen by a National Steering Group that included the Department for Education, the Association of Directors of Children's Services, NHS England (Personal Health Budget and Transforming Care team), young people, local authority representation, the voluntary sector and members of the In Control team.

Harry Barrow, young people's representative on the National Steering Group explains how he understands this piece of work and what it can mean for young people

Simon Cross, Islington and a member of the national steering group talks about what being involved in the project has meant to him and what he hopes to take back to work in Islington

A framework for Keeping It Simple

A simple and consistent approach to working alongside children and young people with complex support needs and complicated family/home lives

Nic Crosby, In Control explains why such a broad group of children and young people were involved in the work of the project

The six sites have worked with a very wide range of children and young people in very different situations. We have used this work to develop a simple framework, at all times recognising the need,

- to be flexible and able to work in different situations,
- to make best use of the skills and knowledge of the local workforce
- to be child and family centred

The framework has to enable those working alongside children, young people and families to work in the most appropriate way, i.e. investing more time on one part or another, reacting to crisis or change and as continually stated not to be driven by a formal planning process.

Tim Keilty, In Control team, explains the importance of not being bound by process and being able to work in ways that fit each child or families situation



Fig 1. A Framework for Keeping It Simple

Listen and Understand

- Invite and welcome the child, young person and the family
- Listen to families, children and young people
- Provide safe, supportive space
- Prioritize this get-together, ensure key people attend
- Focus on what matters for the child, young person and family, what's working well and what isn't working
- Search for capacities, seek connections, be open to 'yes' (John O'Brien / Jack Pearpoint).

HOW THIS WORKED

All the children or young people were already known to services and many had an existing Statement of SEN, 'Looked After' Children plan or other support in place. In this project all "assessment activity" was separated from this stage, which simply focused on giving the family, young person, child and key practitioners the chance to share their life experiences, what day to day life was like, experiences of services and support to date.

Giving space to the family members to speak about day-to-day life was key, supporting them to feel safe in talking about the difficulties they may experience, some of the feelings they may have and what their dreams for the future were.

We could only do this somewhere private where the family felt comfortable and able to talk about their daily lives and experiences. This was particularly important if safeguarding concerns were part of what was to be discussed. Much of what came to light helped all present get a much better understanding of how things were for the family. In Leicester they also adopted the rule that only people who knew the child or young person and family well were involved.

Charlie Connor, West Sussex Children's Services explains how the work with families worked and what was different

Feedback from one parent...

... who said that they felt people now really understood what they had been through and why they did the things they did as a family, and that the planning day had also helped them learn things about themselves and their perceptions of their daughter as well. This parent was also amazed because their ex-partner came who had very little to do with their daughter for many years. The parent hoped it would be the start of a relationship with the ex-partner's daughter again. [...it is]

CHALLENGES

✗ Time

This approach asks services to ensure additional time is given to simply listening to families and those supporting them. Giving the family the confidence to speak clearly without fear of recrimination or having their child's current support reduced or changed.

Concerns about the amount of time invested at an early stage need to be set against the fact that this is a one-off investment, that is necessary due to complexity and complication and should mean less need to re-visit information with the family as the plan develops.

Most families in this project have not had the most positive experiences of support and planning with professionals in the past; feeling 'done to', 'not listened to' and ending up feeling disempowered as no-one will listen to how their lives really are.

Bianca, mother of a young woman who is taking part in the project talks about her experiences

For Bianca the whole process and long meeting were really positive; her daughter stayed all day and Bianca felt it was the first time she had been properly listened too. She also really appreciated the fact the head teacher opened the school in the summer holidays and made time to attend the whole meeting.

✗ Skills

Each planning team were given introductory training and then supported in their work with families including action learning / mentoring support so that by the end of the year each area had a group of experienced confident planners.

Bernadette Simpson, Adviser, Workforce Development, NHS England Integrated Personal Commissioning team discusses the challenges of skilling up the workforce

Andrew Tyson, In Control explains the action learning work he did with the team in Gloucestershire

✗ Participation

The child or young person were always invited to meetings where plans about their own lives were being discussed. Their involvement was crucial in ensuring the work remained focussed on them and their families and acted as a block to the sessions becoming dominated by process.

Getting all the professionals in one place at one time, with an understanding of the importance of what was being talked about was more challenging. There are numerous examples of people not attending at all, or only coming for a small part of the day. For families this felt disrespectful of the investment in time they were making i.e. it's a priority for them, they are giving their time as it is their lives but others don't seem to understand this.

✗ Efficiency

This highlights inefficiency in current systems, when there are so many people needed to make these plans work, (see learning section). This is not about the individual worker who often has an overwhelming workload and is needed to be in a million places at the same time; rather it is about the importance attached to this work by the local area and sharing the priority across all services, teams and people who need to be there.

AGREE AND ALLOCATE

- What next?
- Who?
- Indicative allocation of funding and draft provision
- What resources have I got to plan with and who is going to help me?

HOW THIS WORKED

Agreement of 'What next' is based on the family story and the information gathered through the assessment process whether this means agreeing eligibility for an EHC Plan, a 'Looked After' Children meeting, further in-depth support from one or more service (for example the safeguarding team) or health professionals and setting out a draft plan / allocation of provision to deliver the outcomes agreed with the family (the children and young people involved had one or more existing plans so decisions about eligibility were not needed). The indicative provision / draft plan includes an indicative allocation of funding which can be used as a personal budget should it be requested by the family (for education) or used if from social care and/or health services.

Indicative information (See Code of Practice for SEND 9.102, Care Act and NHS Mandate re necessity of indicative budgets) i.e. information about potential amount is essential as it enables family and those supporting them to explore how best to use the funding to get support and to think about direct payments, *individual service funds* or an organised service managed through the local authority or health service. (See 9.101 in Code of Practice for SEND)

How we approached this for children and young people involved in the project?

We mapped out provision against the four quadrants as shown below, identifying all the provision available including the 'free at the point of contact services' such as GP / Community Nurse support and the opportunities and support existing in the local community. In some cases it was also about identifying what support could be available, especially when it came to the local community wealth where past approaches had not focused on what existed locally.

In working out what support can be available it is important not to simply focus on the funding, although for the children and young people involved it can be a substantial amount of money. There is a need to think about how all provision can be more personalised and tailored to support the individual and their family.

For some young people though the only offer of provision is a residential institution, in this case the personal budget is an alternative to continuing to fund the placement. A simple approach



of 'it won't cost more than the placement' was taken, placement costs ranged from £260,000 to £350,000 depending on the place and support needs (Resource Allocation Systems were not considered appropriate for the children and young people involved in the project due to the complexity of their need and/or for some of the younger participants because their needs were only just becoming evident).

This exercise works both at a strategic level, where an overview of all current spend is being discussed (this can link in to housing support, community investment and transport), and at an individual level where the focus is on identifying funding available for a child or young person.

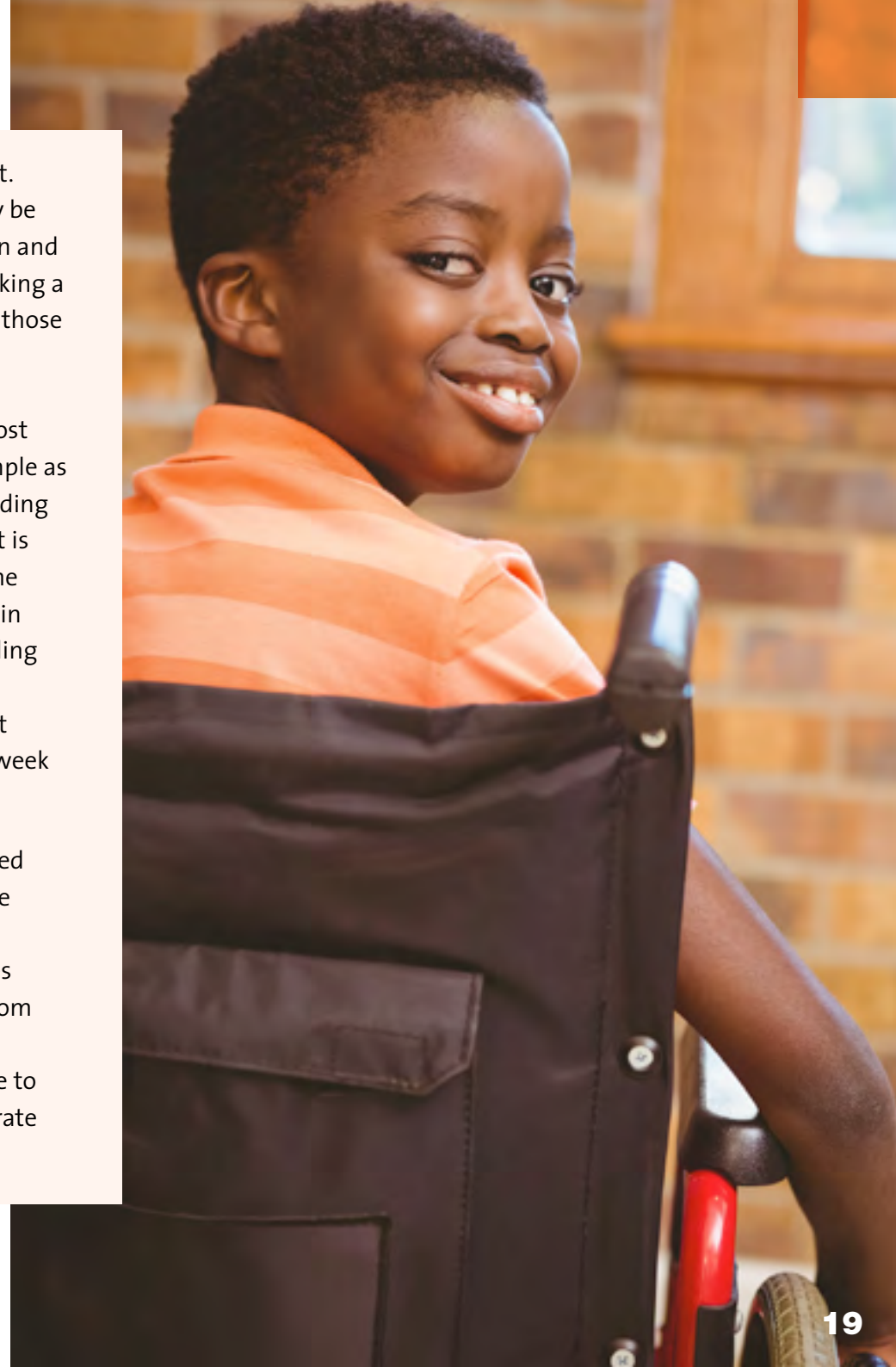
- Make a start by bringing together a core group of people (deciding whether it is a 'strategic' discussion, or to support an individual; agree what is and isn't a personal budget / individualised funding and map out all provision available against the four quadrants.

- For this exercise to work it needs to focus on 'what is happening now' as opposed to what the picture may be in 2 or 3 years of time as this is likely to change as more families take up the opportunities presented by personal budgets.
- Identify and cost the provision which sits with an individual' set this as funding which can be 'flexed' i.e. used as a direct payment, as an individual service fund or organised/managed by the local authority/health service.
- Set this figure as the indicative allocation, then focus on how the rest of the provision potentially available / being offered can be personalised / tailored to fit with the child and their family's lives and the outcomes all have agreed.
- Personalising support such as that at school, from health services and other targeted and mainstream services is likely to be as challenging as

setting an indicative budget. Blocks and barriers will only be removed through discussion and continuing to centre on making a difference for the child and those closest to them.

When starting this work it is most important to keep things as simple as possible so that all parties including the family can understand what is being offered. For example, if the total spend per week on a child in care is £6000 then simply deciding that this can be an indicative allocation with the premise that total cost must come in at £1 a week cheaper.

Over time as the approach is used more, as evidence of appropriate allocations is gathered and as commissioning practice changes and moves away for example from block contracts or high cost in-house services it will be possible to take a more informed and accurate approach.



CHALLENGES

✗ Keeping it simple

Identifying whole cost has been challenging, in part due to different approaches to personal budgets and unpicking large block contracts. Therefore, it is better to keep things simple, for example 'this is what are/are likely to spend on a 'traditional package of support, any new package can't cost more' (unless any re-assessment indicates under-resourcing).

✗ Agreeing across services

Many or most of the children involved in this piece of work have support funded through education, health and social care. Getting agreement on common approaches to personal budgets, and then going on to actually realising the funding to enable delivery of an integrated budget (and hence the support) proved incredibly challenging.

We used the approach outlined above to begin this discussion but the ongoing challenge highlighted just how far apart systems and processes can be. Often key people will be working closely and have a commitment to making things work, however as soon as work goes outside of this core group everything slowed. Decisions were not taken, there was little clear accountability i.e. who was responsible for taking a decision, and large amounts of bureaucracy got in the way.

For example, it took over six months for health services to agree a rise in funding for a young man with palliative care support, whose parent carer was unable to meet the escalation in support needs. This increased stress at home, especially for the young man's mother, his prime carer. It led to his mother considering residential placements which would cost considerably more than an extended existing support package. All this at a time when the young man's health is getting worse. *This situation has now been resolved through the hard work of key people and external support.*

There are similar examples. To the team this highlighted how removed from centring work on best outcomes for the child and young person services have become. The assessment, decision making and any accompanying disagreements all appeared to take precedence over the young person's life and the life of their family.

✗ Accountability

Accountability and clarity, and, who and what this meant varied across the six sites. Put simply, where the project had strong senior leadership committed to making the project work, it worked. Where responsibility was given or placed with someone without the authority to make things happen with partner organisations or services the project struggled to gain momentum and to follow a coherent path through to making things better for families.

Richard Holland, Cambridgeshire Children's Services explains the need for strong leadership and accountability when it comes to making this new approach work.

MMFMH Tim Keilty - Planning

Leicester recruited a diverse group of people at the beginning of the project.

Tricia Nicoll explains the work in Leicester in setting out a vision for how things should be for disabled children and young people in Leicester.

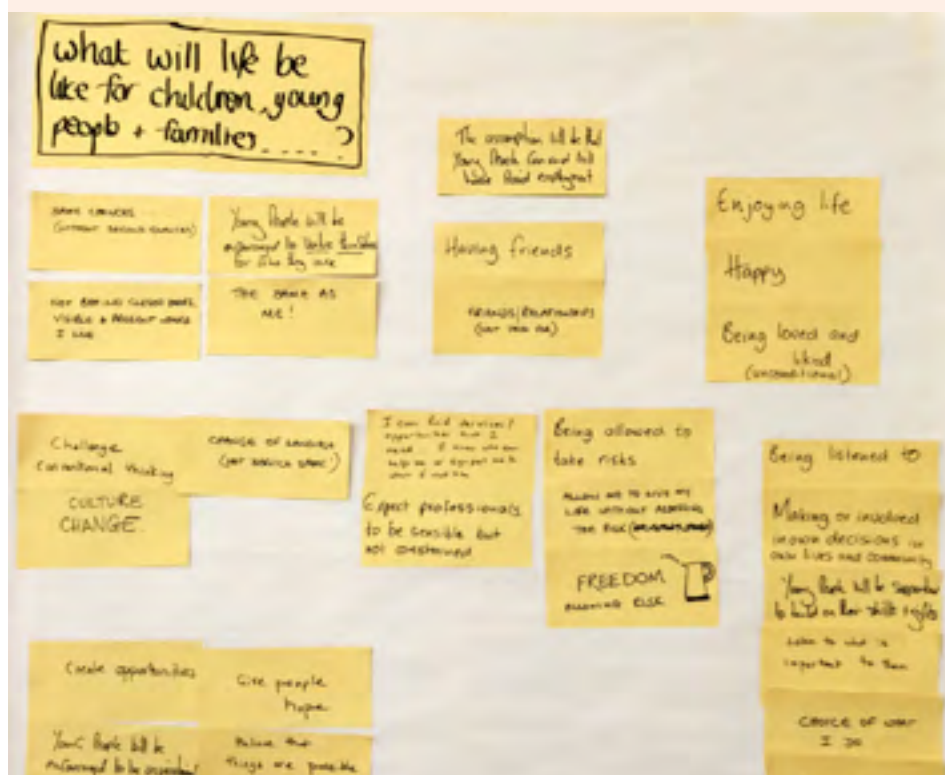


Fig 3. Leicester, Me My Family My Home, planning session, June 2015

PLANNING TOGETHER

- Child, young person and family centred
- Time invested in exploring the whole breadth of local opportunities for inclusion
- Emphasis on investing in the family
- Setting out a support plan using funding and local provision
- Working hard to avoid over reliance on specialist services

Sam Sly, In Control explains a simple approach to life planning

Tim Keilty explains the basics of the approach to planning with children and young people in Middlesbrough

Josh Hang Gong shares his experiences of the planning work with families in Cambridgeshire

Planning with children, young people and families has been the biggest investment of time for both the In Control team and those in the six local areas.

This has needed up to 2 days of time per family due to:

- the complexity of the situation and getting the right support from all key people and funding to fit together; services moving away from fixating on their own outcomes to understanding that the focus is 'whole life'
- the newly trained group of planners (and families) with mentorship getting used to a new way of working and, to start with, wanting to follow the approach they have just learnt. With familiarity comes more skills and flexibility, enabling the planning process to be even more driven by the child and their family approach to the use of time
- managing to get all the right people in the room / at the table at the same time. This has proved a continual problem, in part to the clashing of priorities and in part to the priority set against this piece of work. In part, this has been down to which service is leading the work and wider relationships with others.

Giving time to all, and focusing on good planning especially when thinking of children and young people in much more complicated situations may appear to stretch official time lines (e.g. 20 weeks or 45 days). However, front loading an investment of time will produce better information, giving everyone who knows the child and family a chance to contribute and will reap benefits later in the process. This is not about additional time but making better use of the time available to pre-empt discussion, challenge and people not feeling included at a later point.

SERVICE LAND GOGGLES



At its core, our approach is one of stepping outside of how services have worked in the past, moving away from historical culture and being person centred. In our training we explain this as taking our 'service land goggles' off, i.e. relating to people as people, to family members as we do to our own family members. Although it might seem somewhat off-beat, the idea of service land goggles has proven to be an effective way of illustrating how we often relate differently to people due to the predominant culture of the service we are working for, and how important it is to step away from this.

✗ Key elements of planning:

1. Remember you are a human being not just a worker in social care – take your goggles off and connect with people as people
2. Relentlessly focus on gifts and capacities
3. Think about relationships and the real world – assume solutions will exist in the 'ordinary world'
4. Help people come up with their own solutions – 'what would it take?'
5. Make it happen, and make some things happen very quickly – 'you need a bed? We'll get you a bed tomorrow.'

To summarise, this is the key part of the whole process, good plans promote safeguarding and risk taking, good plans mean families can feel that their child and themselves are at the centre and that they have been listened to and good plans present the best way of achieving outcomes. It takes investment and capacity. As the workforce evolves and integrates there will be much greater opportunity to look at how planning is done and resourced and to build a skilled group of planners able to work closely, in a person centred way, with the delegated responsibility they will need to facilitate plans that will lead to improvements in support and in family/home lives.

‘Planning together’ includes having a varied offer of support from different providers and access to the whole menu of mainstream and universal opportunities and activities:

DEVELOPING SUPPORT, PERSONAL ASSISTANTS AND PROVISION

All six areas have identified a dearth of skilled and appropriate support. This was combined with a lack of engagement on the part of education providers (schools and colleges) and a challenge for providers in the adult world in being part of the EHC plan (predominantly children led work and support). This means there are few if any providers equipped to think about fully integrated funding and support, for example managing a co-funded Individual Service Fund.

Extract from Cambridgeshire’s Exit Strategy relating to growing the number of facilitators and partnerships with adult social care services.

Through the process of the regular steering groups, we have been able to get the interest of our adult services who are interested in how they are able to use the plans to continue to support the young people once they turn 18. Our Mainstream LAC services who are also keen to think of ways that they can use this to support the young people within their services. Adult services have been an active part of the steering group and also attended planning meetings and have identified possible families interested in undertaking and completing personalised plans. Educational colleagues have also been supportive of the project with an interest of how it can be worked together to support the EHC planning processes, instead of duplicating. Adult services in Cambridge are also committed to the Me, My Family, My Home project they are to develop plans for and identify workers in the service to act as facilitators.

A number of activities were taken forward to address this:

- information sessions for local providers followed up with discussion where providers put themselves forward. For Example: Devon Children's Services are running a set of workshops addressing gaps in their local provision to support children and young people with learning disabilities and autism.
- working with parents and family groups to think about recruitment of personal assistants (Leicester, West Sussex)
- working to address concerns of schools for example and build an understanding that 'whole life' outcomes and support can and should deliver improved learning outcomes and hence encourage schools to get involved
- Example: A school in Cambridgeshire opened during the summer holidays and the head teacher attended a planning meeting for one young person. Feedback from all parties was very positive about how it gave them a much better and in depth understanding of the young person's life and that of their family. The head teacher was very positive about the planning day.
- engaging with local CCG's, addressing concerns around clinical governance and delegation of key support
- Example: Peoplehub, supporting families and people with health support to use personal health budgets and access advice and support

Living my Life

This section is best left to those involved in the project to talk about what differences this approach has made to their day to day like.

For Melanie, mother of twins it has meant being involved in recruiting the right support for her daughter Jasmine, feeling much more in control of how things are working, making sure the staff get the right training and giving her more time to spend with Noah her other twin. However for Neil and Jude, parents of another set of twins, things haven't moved so swiftly, mostly because of confusion about planning and the statutory EHC process in place which has led to debates about who is the lead.

Joanna and Tanya talk about their experiences in Middlesbrough and the difference to their lives today

There are many more positive stories where families and those supporting them talk of the importance of listening and then acting on what people say, on being involved in recruitment, on being able to look ahead with more confidence. However things haven't always worked out and there are some families where progress on the project has stalled or being halted and this is clearly the fault of the local services.

Family A – Middlesbrough

This family are new to the UK after seeking asylum, they have 3 children under the age of eight, one of the children has Autism – they became involved with Me, My Family, My Home when concerns about the children almost resulted in all three children being taken into care.

We didn't know anything around the UK. We found ourselves in an awful house, we didn't know anyone or do anything other than go to the supermarket and the park. We would have a great time at the park, but then I'd think, "I've got to go back to that house"

My little boy said, "This isn't a nice house the walls are broken" it was difficult to look after the children in such a bad place, we were struggling and I felt upside-down inside.

Things got so bad that we were almost going to lose the children. That is when I got involved in this work (Me, My Family, My Home)

The biggest thing that happened is that they helped me find a better house. It is

easier to look after the children and I get support from the Home Support Team – to help me with activities with the children but I decide what support I get. I don't want help with the housework I want help with the children's home work. Having a budget really helps so we can get this support but also things together as a family and get rid of the stress.

We are in a better house, in a better area and the children are happier at school. The head teacher of the school asked me if I wanted to go to church with her, I don't know why she asked me! I go to the church with the children. After the service, volunteers look after the children and watch DVDs, the adults chat about this and that, I'm making friends and starting to feel like we belong.

Review and learn

Of the work in the six sites only that in Middlesbrough is far enough into the project to be reviewing how support is going for the different children and young people involved. With children and their families often leading fairly chaotic lives there is no 'formal person centred review' process in place. With each family having a link worker the responsibility for making sure the support and any personal budget being used is working sits with the link worker. They all make sure that if there is a meeting about the child or young person that they are invited to attend and participate.

Any structure for a review meeting will be along the same simple lines as information gathering and planning, using two key questions; 'what is working?' and 'what is not working' all the key issues can be raised and recorded and any action needed can be agreed there and then.

At the core is the attendance and participation of the key people; family members, children and young people.

What we have learnt

FAMILIES

- We must unshackle families. They are their own greatest resource.
- We need to listen to them and support them to learn how they can play a part in changing things - by doing this they will help the system to help them.
- This is difficult because, so often, we found that families were alienated and don't see why they should be expected to help a system that has failed them. We need to regain their trust.
- Part of the reason for their alienation is that so many of the families we met on the project find life so difficult. They are ground down by various combinations of sleeplessness, lack of money for the basics, the constant need many parents have to carry out personal care tasks, or cope with distressed children. The overriding sense is that the system is not supporting them in all of this and they are on their own – and to make it worse, they have to deal with an unfeeling bureaucracy which is more interested in enforcing arbitrary rules, than it is in providing genuine, practical support.

Alison Nuttall, West Sussex reflects on the key learning for her as lead commissioner across Children and Adult Services

Matthew explains what being part of the Me My Family My Home project means for him and how he still has many worries about the future.

- We need to help families become more resilient. The new legislation should be a call to those working in the system to think through their role – is it our role to stand alongside these families who find life so tough; or are we simply publicly-appointed guardians of scarce resources, with no obligation to engage emotionally with the people who approach us for help?

BEING PERSON CENTRED

- Person-centred talk is easy – doing it justice requires something different and more profound.
- ...Different but not necessarily new. Many practitioners have been working in a person-centred way for a long time. Sometimes this has been celebrated by their colleagues and managers, more often it has been carried on below the radar.
- The system has frustrated these able practitioners, and it's got worse as we've seen the need to bear down further on budgets and to be more controlling of professional practice.
- Some of the great practitioners are newly qualified workers. Many new workers bring enthusiasm, idealism and recent learning.

COMPLEX AND COMPLICATED

- Everywhere we worked on the project, the system remained too complicated and difficult for families to understand or navigate. Many staff don't fully understand it either, often concentrating their attention on their specialism or their agency only. This is a real problem and we need to find ways to open eyes and minds to a wider perspective.

- This is very often compounded by poor information for the public. The Local Offer has helped in some places (eg West Sussex) but not all Local Offers are fit for purpose and a clear Local Offer does not always equate to simple, easy-to-navigate systems and processes.
- Working across agencies is essential, but it also adds several layers of complexity and challenge.
- There were examples of good inter-agency working from the project – but full person-centred integration of support systems remains a way off in most localities.

PERSONAL BUDGETS

- There are major issues with making available personal budgets:
 - Too often there are “blanket rules” for what budgets can be spent on.
 - Identifying funding which can be used as a personal budgets was a confusing discussion, definitions, block contracts and mis-understandings created blocks and slowed the project down.
 - As yet few authorities have mechanisms for allocating personal budgets ACROSS agencies.

Trudy Reynolds, PHB lead at NHS England explains Personal Health Budgets

MAKING GOOD PLANS

- Making good plans with families is often undermined by:
 - Not putting families in charge of the process.
 - Not enough preparation before a planning session.
 - Being more interested in ticking “EHC process” boxes than figuring out what is the best way to plan with this family in this situation.
 - Doing things in too much of a rush in order to meet statutory time-scales: (this is a major system-flaw, with a simple fix available).
 - Not listening and observing families closely enough. Good planning = good listening.
 - Not making sufficient use of “natural supports.” Lots of noise about “assets and strengths” – less action.
 - Not standing with the family – too much “professional distance” and a move away from statutory workers as advocates.
 - And too much distance from the process which “signs off” the plan. Are Panels, as traditionally conceived ever a good idea?!
- The project demonstrated that good planning is very much a possibility; and that the good plans are absolutely compatible with statutory requirements, BUT a good plan is family-owned and there may need to be a process where this is translated to meet statutory requirements and for agency purposes.



A NAMED PERSON

- Families need a keyworker, sometimes now called a Single Point of Contact (SPOC), who can pull things together and answer their questions, without either side worrying about which agency the worker is from and therefore who they are representing.
- There are examples of how this is developing, but in most of the project sites there is still some way to go with this

GETTING THE RIGHT SUPPORT

- “Providers” have a vital role to play, they often know the families best. “Providers” here include schools, short-break services and other mainstream community groups like clubs and voluntary associations. The key providers will be different for each family. Too often providers are seen as a “resource to be used” rather than partners in the process. There needs to be a culture that engages with and nurtures the widest possible provider community to bring genuine choice.

LEADERSHIP

- Probably the most important thing of all is “leadership.” Things go well where there are visionary, resilient leaders who drive change through, but we need a sophisticated understanding of what this sort of leadership really means. For one thing: to change the system in a way that is sustainable over time requires that leadership is not vested in one individual, we need a *culture* that maintains change and part of this must be the means to grow family leaders.

Debbie Buckwell, West Sussex reflects on the learning for her in her role as Strategic Commissioning Officer for Disabled Children and SEN

Looking back to look forward

Looking back to look forward – Returning Children to Middlesbrough¹. The sites participating in the project were clear that this year of intensive support was a start for them on the road to embedding this approach as their standard way of working, not just for those children and young people focused on in this project but more widely.

They wanted to learn from Middlesbrough, who introduced a similar approach 2 years ago. Their experience has demonstrated many of the challenges of getting started with this approach but, now, 3 years on have with well over 40 children and young people having been involved. Their success has far outweighed the challenges with much improved outcomes for children and young people and clear efficiencies being generated. Ofsted has recognised the success of Middlesbrough's work:

“strong practice by the local authority that is promoting positive outcomes for children and young people by helping them to return to live closer to their families, friends and community”

Jenny Dalby, Service Development Manager, Disabled Children's Services, Middlesbrough summarises their experience below:

WHY DID YOU MAKE A START ON THE RETURNING CHILDREN TO MIDDLESBROUGH PROJECT?

Middlesbrough has a high number of “Looked After” Children, and a significant number are in expensive residential or agency foster placements. For some children and young people this is the best option in terms of keeping them safe, meeting their individual needs and achieving their full potential.

However for others it seemed possible that their needs could be met more effectively and more economically closer to home. Placement costs place a significant pressure on the Council's Budget at a time when Middlesbrough, like all local authorities,

is experiencing budget pressures. Many young people return to Middlesbrough as they approach adulthood, and it seemed sensible to explore whether a new approach would achieve better outcomes for young people while spending money more effectively. For example, it might be that a child placed at a cost of £3000 per week could be returned to their family at 50% of this cost if a creative and innovative plan for the whole family were created.

In Middlesbrough we have made excellent progress implementing personal budgets for children with disabilities and have seen the success of this approach for children, their families and us as a Local Authority. Personal budgets had not really made an impact with other groups of children so we decided to pilot this approach with “Looked After” Children in out of area placements in order to return some “Looked After” children to their homes or closer to Middlesbrough. We also explored using personal budgets to prevent other children becoming “Looked After”.

WHAT WERE THE KEY THINGS WHEN YOU STARTED THAT YOU FELT YOU COULD BUILD ON?

We had developed our experience of personal budgets with children with disabilities, through which we had built better relationships with families and had a lot of the discussions around what you can buy with a personal budget. We were used to spending council resources differently. We also have some fantastic social workers in Middlesbrough and talented staff within our Resources Service who understand what it takes to make personal budgets work.

CAN YOU EXPLAIN IN BRIEF TERMS HOW THE PROJECT WORKS?

The project has adapted and developed over the years but essentially we consider young people for the project who want to return home, their families want them to return home and others in their lives including professionals think this is a safe, positive thing to work towards. Importantly our thoughts and decisions around a return home being ‘safe’ are based on a child returning home with significant support in place. We then do some good child centred planning with the young person and their family (in partnership with their social worker and others) – we don’t have a resource allocation system to decide budgets but we do know the cost of children’s current placements. When the plan has been developed and costed - it is agreed at our monthly steering group meeting.

The planning is facilitated mainly by staff from the Resources Service supported by Tim Keilty. The use of resources in the plans differ from child to child but generally are geared towards what it would take for a return home to be successful, this could be:

- A season ticket for Middlesbrough FC, cinema cards, short breaks or other leisure activities to give children and families something to look forward to and positive times together
- Incentives for young people to get them to school or engaging in activities
- Practical support like beds, washing machines or help with rent arrears
- One to one support for children and families from our in-house team

We also support young people for whom a return 'home' is not suitable to move closer to Middlesbrough. Increasingly we are using personal budgets to support children and families who are on the verge of entering care, supporting them to remain together at home with practical support in place.

LOOKING BACK, HOW DID YOU KEEP GOING IN THE FIRST YEAR WHEN PEOPLE WERE STILL BEING CHALLENGED BY THE PROJECT?

In some ways we were lucky that one of the first young people we worked with returned home successfully - this showed that our approach worked for young people and families but also generated some efficiencies for the council.

I don't remember it as being too challenging - in the first year or so we were just quietly getting on with it, not really drawing too much attention to ourselves. Knowing that the steering group were behind the work helped enormously, service managers, team managers and front line workers who all understood and supported the work meant we could deal with any issues as they arose. Having external support from In Control was helpful, this meant that we were not trying this on our own but felt we were part of something bigger. We must have worked with five or six young people in that first year with varying degrees of success, but enough success to prove that we were doing the right thing, and were on the right track.

CAN YOU SAY A BIT ABOUT HOW IMPORTANT IT IS TO BE OPEN AND HONEST WHEN THINGS GO WRONG?

We are conscious that this is delicate work, working with vulnerable young people and families who can feel let down by the system. We are also very aware that social workers are working extremely hard to get the best for children in very difficult circumstances. Therefore it is not so much about things going 'wrong' or 'right' but finding some balance in how we learn from both of those situations and being open and honest about our success and failure. For some young people a return home is the best thing, for some young people remaining where they are is exactly what is needed. There is rarely a success story which hasn't had elements of failure entwined in it!

WHAT HAVE BEEN THE MOST MEMORABLE SUCCESSES IN MIDDLESBROUGH OVER THE PAST 3 YEARS?

There have been some great examples of success, a few of them documented in this report – notably Amy one of the first young people involved – still at home, astounding everyone with GCSE results, thriving at college and now thinking of her next steps as a young adult. The three young children on the verge of long term fostering/adoption now settled at home with their mother in a new house, the children doing well at school and their mother

becoming part of her community. There are many others. As well as the success for children and families I've seen the staff team in Middlesbrough grow in confidence and develop their skills further.

HOW DO YOU SEE THIS WORK BEING TAKEN FORWARD IN MIDDLESBROUGH?

We've made steady progress and we just need to continue that progress... We need to ensure that we think about this approach in all the work that we do, but we also need to be realistic and remember that this approach will not work with all families ... there will still be children and young people who need the support of a residential placement or who need to be away from their local area.

WORDS OF ADVICE OR TOP TIPS FOR SERVICES NEW TO THIS BUT WANTING TO DEVELOP SIMILAR APPROACHES?

✗ Have Control

Decisions need to be made quickly, resources (including staff and finance) need to be available without a long drawn out process of seeking agreement or tendering for a service. We have benefitted from having an "in-house" service which we can use and having one manager responsible for all decisions.

✗ Take Time

You need to get to know the family, to produce a good plan, to understand the strengths of the staff you are working with and have the right systems in place.

✗ Do not be distracted

Avoid creating criteria - or policies and procedure about what you are doing - keep it open and general. Do not produce guidance which will stop you doing what you want to do.

✗ Find a partner

Someone from outside your authority who will see what you are doing with new eyes, ask difficult questions and be seen as independent by families. Try to get them to write reports for you so you can focus on other things!

✗ Be determined

You need to be able to challenge others when they say it is not working, and follow the plan. There will still be problems and difficulties (just as there would be if the child was in residential care) but most of these can be overcome.

✗ Be Brave

There are risks which need to be shared and discussed - there are challenging decisions about how we spend Council money - you need to be able to deal with this.

✗ Focus on success

There will be good stories to tell about outcomes for young people - you need to make sure that their voice is heard. There will be savings made - you will need to make sure that people know this and do not focus on money spent.

Making it work

It's all very well to set out what is wrong with the system and say how it should work, but how do we actually change things so that they really are different? We are where we are today: for many in local authorities this is a really difficult time, with very high workloads and lots of stress. How do we realistically turn things round? How do we move away from the over-complicated, unresponsive and process-driven monolith we have today? How, in other words do we develop a set of practices and procedures which do what it says in the Children and Families Act 2014 that is, enable children and families to have a good life?

- 1. Think about people first.** Put yourself in other people's shoes, listen to them and try to understand. People here means everyone: families, professionals, staff, other agencies and the wider community.
- 2. Build trust.** Show that you trust these people and get them all working with you on changing the culture and the system. Of course you may be let down occasionally but that is not as bad as building a system based on mistrust and suspicion.
- 3. Work with, not for or against.** Pull down the wall dividing families and professionals. Families generally like good practitioners because they know they are there for them and will stand with them. Make this normal.
- 4. Build a community of families.** Invest in them, listen to them, recognize their value and give them important jobs to do as part of the process of change.
- 5. Recognize and reward professionalism.** Value your staff, don't ignore their concerns about change: you can't help families in distress if your staff are in distress.
- 6. Think whole system** - in the context of this work, that "system" largely means education, health and social care. But don't ignore community, housing and the rest of civic society.



*Nicola Gitsham, NHS England IPC Team
explains what ‘think whole system means’
in the context of support for children and
young people*

- 7. Keep it simple.** Don't overcomplicate either the change process or the end point you are aiming at. We are seeking a very simple and straightforward set of outcomes: that children and families in our locality are safe, well and thriving. Don't be afraid to slay a few sacred cows as you go down this path - actually not too much is really sacred any more.
- 8. Communicate, communicate, communicate...** From day one of the process.
- 9. Box clever.** You will meet people along the way who don't agree with your core values or who have vested interests in the old approach. If you can't persuade them - give them those light bulb moments - smile and work around them.
- 10. Remember** that whilst this will be seriously hard work, make sure that that's not all it is. Keep your sense of humour and enjoy the ride.

Conclusion

This last year of work is a good start, much of the challenges and issues we have encountered we fully expected, as ever the resilience of families and individuals has shone through and we are all grateful for all the hard work of the people in each site who have given their all to make this project work.

Balanced with this positivity though is impatience in a system and approach which fails fundamentally to centre its work on making a difference for children, young people and families. As much as we have met and worked alongside some fantastic child centred workers, managers who remove barriers and remind those who work with them that they are solely here for the children and families they support we have encountered blocks, many of which have no basis in law or legislative guidance, barriers, resistance and obstruction. For the whole team, which includes all those out in the six sites who have worked so hard it is simply not good enough to continue to think it is okay to stand in the way of children, young people and families getting the support they need to live the lives that make best sense to them.

If we are to succeed with a 'whole life whole family' approach, if NHS England Integrated Personal Commissioning programme is to succeed then we have to be clear. It does not matter what system, process, pathway or toolkit we put in place, if we do not address

the basic failings of the system to recognise that it's about children and families and not about ticking the right box, reaching the right target, or achieving a glowing inspection report. If we do not tackle this as a whole community then we are simply 'rebadging' the historic failures with a new system which will deliver exactly the same failures and we will continue to waste millions of pounds on support that doesn't work, on projects which never deliver lasting change and sadly we will see an ever increasing number of families who we are failing.

So, with there being not one single legislative block to working in a whole life whole family way, with there being a clear need to change the way we work, with there now being good evidence of what really works, much of which comes from the last year of work, it's now a case of 'Just get on and do it'.

In Control | 2016



Just get on and do it...



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