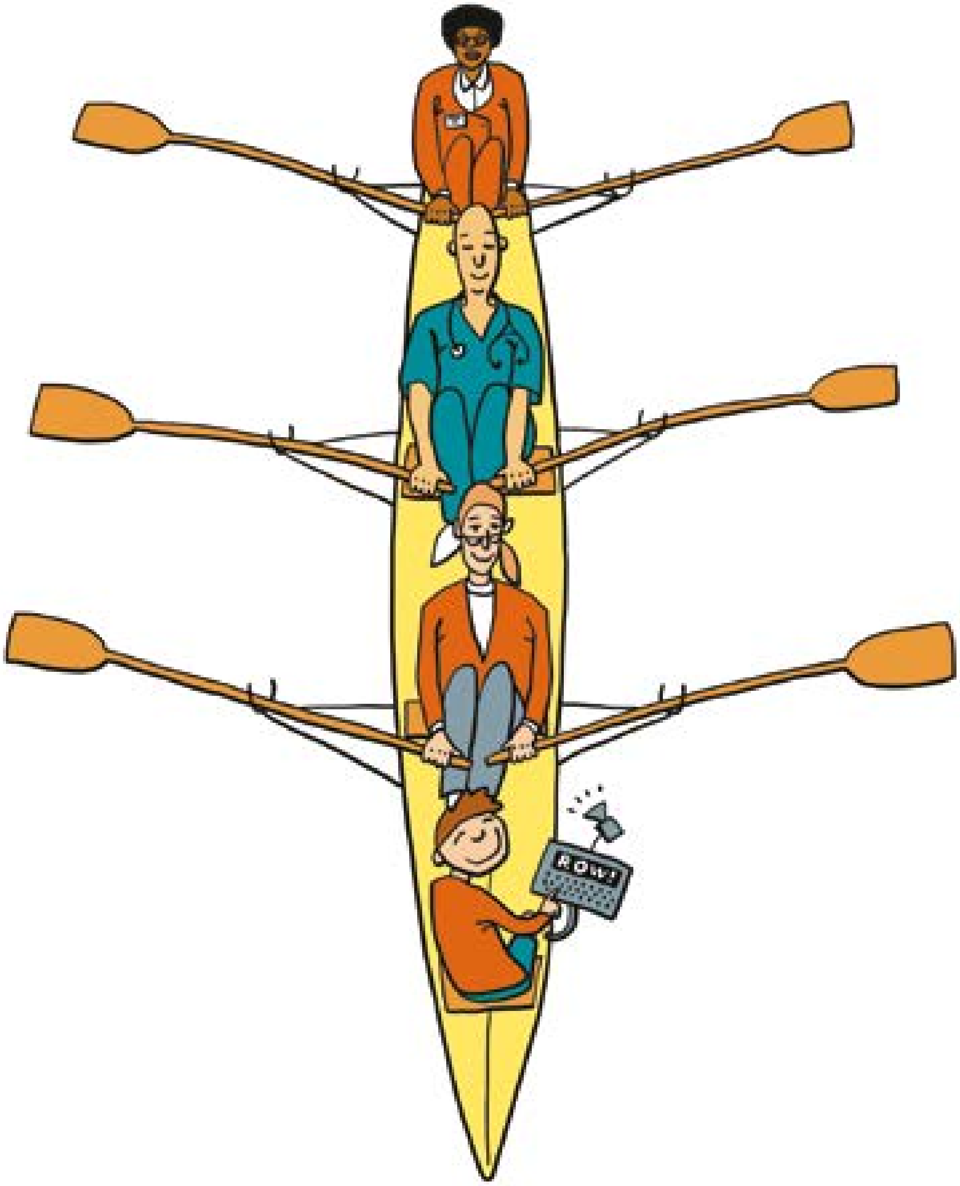
Council for disabled children



It takes leaders to break down siloes

INTEGRATING SERVICES FOR DISABLED CHILDREN

by Amanda Allard, Andrew Fellowes, Anna Gardiner & Sarah Hart

Acknowledgements

This report is the culmination of a number of years' hard work from the Health Team at the Council for Disabled Children. However, it would be remiss not to give special mention to Andrew Fellowes who had the original idea for the study and conducted all of the field work.

Thanks go to Professor Jeremy Parr, Dr Lindsay Pennington and Dr Gregory Maniatopoulos at Newcastle University who supported us and provided quality assurance on our approach.

But most especially thanks go to those sites who took part and were willing to have their approach to integrated working put under the microscope in order support others and improve future practice.

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Contents

Executive summary

Over the past decade, successive governments have brought in a range of legislation, policies and programmes in an attempt to deliver on a vision of coordinated, person-centred care and better outcomes for children and young people with SEND. However, despite this visible drive towards integration, services for children with SEND remain fragmented.

Following consultation with 76 education, health and care professionals and parent carers in three local authority areas, this report considers why the task of integrating the design and delivery of services around SEND is proving challenging. It also identifies the key factors enabling or hindering progress.

Local authority and NHS commissioners are compelled to integrate services by a range of legislation and national programmes. The desire to address the role of wider, external factors in determining our health and wellbeing, has additionally led to efforts to coordinate across whole 'population health systems' (Alderwick, Ham, & Buck, 2015). This approach is especially relevant to children and young people with SEND who, not only access a range of services across health, education and social care in relation to their SEN or disability, but are also more likely to belong to other vulnerable groups.

However, we know that in practice, the reality of integrated working between different services and agencies, such as NHS and local authority services, children's and adults' services and specialist and universal services, is challenging. The many services accessed by children and young people with SEND are subject to different legislation, funding models and accountability mechanisms that drive different organisational priorities. This means that in reality most initiatives trialling more integrated systems have focussed on adults where only health and social care need to be integrated.

FINDINGS

- The system around SEND, both nationally and locally, is highly complex and fragmented and those who work in it face multiple practical barriers to integration.
- An additional barrier is the historical focus on specific cohorts or services, which is deeply embedded and difficult to shift. For many, funding pressures also exacerbate this problem.
- Leadership is the most important factor in enabling (or hindering) integration – leaders can unite services and agencies around a whole system approach to SEND and wider vulnerable children's services.
- Currently central government is seen to provide insufficient leadership with policies and change programmes not being aligned ahead of implementation.
- Without effective leadership, front line staff and middle managers are forced to devote significant time and energy to finding 'work arounds' to ensure support for children and families is joined up.
- Good quality population data is vital to developing a whole system approach, as well as measurement of shared outcomes.
- There are a number of other ways that local areas can try to overcome the complexity of the system and enable integration between services – but these are most effective when part of a wider strategic vision. Without this, they will generally be activities that are additional to professionals central work role.

MAKING IT WORK

Despite the challenges presented by the system, there are a number of ways in which local areas are working to overcome these complexities and enable some level of integration.

There are various forms and levels of integration. Care can be integrated around the individual, across multiple services, or system-wide. It may be low level - introducing improved referral pathways and information sharing processes between two teams, or as high level as formally merging multiple organisations.

We have come across various initiatives and arrangements, both through this research, and in our work with local areas across England. In all cases, they appear to work best where they are supported by senior leadership and a clear strategic vision.

Joint commissioning arrangements:

- Commissioners are increasingly coming together to **jointly commission roles** which support joint working – most notably the Designated Clinical Officer for SEND (DCO).

- Participants felt that formal **Section 75** Agreements make integration 'harder to walk away from' and therefore increase commitment to joint working.

- Commissioners can also support joint working through committing to an **Outcomes-Based Commissioning (OBA™)** approach whereby commissioners task multiple providers with delivering on the same key outcomes.

- There are a number of **innovative contracting models** that can support outcomes-based commissioning, such as:
  - › **Alliance Agreements**, whereby different providers who already have a contract with a commissioner are brought together to work towards shared outcomes for a specific population. This model encourages providers and commissioners to work collaboratively.
  - › The **Accountable Provider Model** or **Prime Contractor Model,** in which one provider is commissioned to deliver an integrated pathway of services designed to achieve a defined set of outcomes. This usually involves sub-contracting other providers to support different elements of the programme/service. Sub-contractors are held to achieving the same defined outcomes.

Joint working arrangements:

- For participants in this study, **co-location** (the physical placement of teams in the same building) helped teams to understand each other's perspectives and develop their work in a more integrated way.

- A set of case studies by the Social Care Institute for Excellence (SCIE) has highlighted the value of **multi-disciplinary teams** in driving integration. SCIE stresses that there are different ways of doing this, including:
  - › formal arrangements, teams are brought together under a partnership body;
  - › the introduction of systems and processes that enable professionals across different organisations to come together to manage complex cases.
  - › the **'key worker'** system whereby care is coordinated by a named worker.

- **Formal multi-agency decision-making processes** should enable different partners, for example from the local CCG and local authority, to navigate differing referral processes, threshold criteria, delivery models and funding mechanisms in order to agree on and deliver an appropriate package of support for a family. In successful examples, panel representatives were supported by clear, multi-agency arrangements and processes agreed at strategic level.

Involving children and families in decision-making:

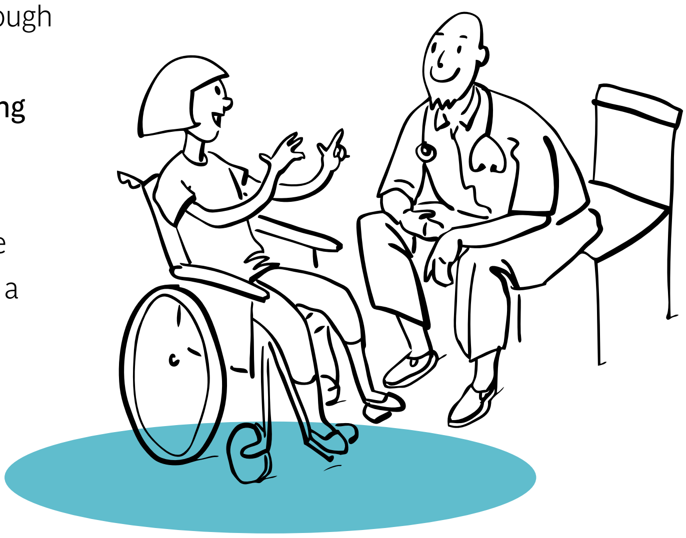
- **At strategic level**, co-production with parent carers was achieved by **involving families from the earliest stages** through workshops, meetings, consultations and representation on programme boards. Parent carers were also involved in day-to-day work through representation on multi-agency panels or governance boards.

- **At an individual level**, participatory approaches to decision making include the early initiation of a **person-centred conversation** with the child or young person and their family. Following this, it's important to ensure the conversation informs the rest of the resulting process and support package, and provides a basis on which to unite agencies around holistic needs, outcomes and aspirations.

- **Involving children and young people** at strategic level was felt to be more challenging for participants, but all areas were making efforts to include young people in these processes too, or to seek their advice through workshops and engagement groups.
  - Some local areas have established **Young Commissioners** groups to support commissioning and procurement activities, undertake research and make recommendations about services from a young person's perspective.

- Crucially, engagement with families must be meaningful, with a **clear, pre-determined process** for feeding any outputs into strategic planning. This again links to leadership and strategic-level commitment to change.

- In addition, local areas must be mindful of **not shifting the burden of coordination** onto families: the effective engagement of parents and carers must be one of a range of strategies for supporting the integration of care at individual level, and cannot substitute broader efforts to join up services.



Recommendations

LEADERSHIP

Senior leadership within national government and NHS England should:

- Review and align key priorities across all national programmes impacting this group of children and young people; then align performance measure across programmes.
- Ensure that when introducing any new change programmes work is done to align that programme with all related existing requirements.

The **National Leadership Board** for children and young people with high needs (reporting to the Minister for Children and Families), should consider what further steps need to be taken to ensure that leaders in local areas prioritise integrated commissioning to deliver integrated services.

DATA AND INFORMATION-SHARING

National government and NHS England should review and align reporting requirements for national programmes in order to:

- Facilitate a shift towards outcomes-based data that will help demonstrate the value of delivery beyond simply activity data and outputs;
- Reduce the reporting burden on local areas wherever possible.

We also emphasise the need for **national government and NHS Digital** to continue to support and incentivise data collection on children and young people with complex needs to build a clearer picture of the needs and outcomes of this group, and to develop more integrated means of gathering and presenting this information. This reflects the more detailed recommendations made in our report, *Understanding the needs of disabled children with complex needs or life-limiting conditions* (Pinney, 2017).

NHS Digital should identify whether or not it is possible to update their information sharing resources, to include agencies working with children, without an amendment to the The Health and Social Care (Safety and Quality) Act 2015 (see Appendix 1) which introduced a legal duty requiring health and adult social care bodies to share information where this would facilitate care for an individual. If possible the resources should be updated with immediate effect.

If an amendment is required, **national government** should seek to amend The Health and Social Care (Safety and Quality) Act 2015 to extend the legal duty to education, health and care bodies where this will facilitate care for a child.

FUNDING STRUCTURES

National government should rapidly review local funding for SEND children's services as a response to concerns stated in this report and wider publications, and in the media.

DHSC should require CCGs to report separately on their spending on children's health services.

NHSE must hold CCGs to account in terms of progress towards their set goals, ensuring they give sufficient priority to services for children.

DfE and NIHR should commission a cost effectiveness study of joint strategic planning and joint commissioning arrangements in order to support the case for change.

UNIVERSAL SERVICES

Ofsted should ensure that its review of the schools inspection framework includes a greater focus on pupil health and wellbeing and the outcomes sought for pupils with SEND. To incentivise schools to meet the wellbeing needs of all pupils.

The Government should ensure that commitments made to ensure that all health and social care staff have training on learning disability and autism adequately covers the children's workforce and includes education staff so that all professionals know how to support children with SEND.

SUPPORTING AND INVOLVING FAMILIES IN DECISION-MAKING

CCGs should jointly fund Information Advice and Support (IAS) Services to ensure that they can adequately fulfil their statutory duty to provide advice and support across health as well as education and care services.

CCGs and local authorities should recognise and fund local parent carer forums (PCFs) as a well-established source of expertise, who due to their own personal experience, are ideally placed to support a holistic approach to supporting children and young people with SEND.

Introduction

Children and young people with special educational needs and/or a disability (SEND) and their families have a consistent request: that they are supported to achieve the best possible outcomes through access to the right services at the right time.

For this to happen, they need the people who commission and deliver services to listen to them and take them seriously. They need different professionals, services and agencies to coordinate their work so that their care can be 'joined up' and personalised according to their needs and aspirations, and so that families are able to make decisions about their lives with minimum disruption.

***"So, an outcome that we are looking for from a parent perspective is that services work together. What we really need is when [our child is] having a wheelchair assessment, we need to have the wheelchair service, the physio and the OT all in the room together with us, so that we are all on the same page as to what changes are being made to the wheelchair, rather than wheelchair service is going to change the wheelchair, the physio then sees the wheelchair a week later."* Area C**

Over the past decade, successive governments have brought in a range of legislation, policies and programmes in an attempt to deliver on a vision of coordinated, person-centred care and better outcomes for children and young people with SEND. Underpinning all of these initiatives is a consistent focus on the integration of different services around the individual, putting the voice of the child or young person and their family at the heart of care-planning.

There is broad support for the principles of joint working and integration at local level, and many local areas are devising their own methods for supporting coordination across the different services accessed by children and young people with SEND and their families.

However, despite this visible drive towards integration, the system around SEND remains fragmented, and families remain concerned that these efforts are failing to deliver on the vision of appropriate, well-coordinated support, crossing organisational boundaries and leading to improved outcomes.

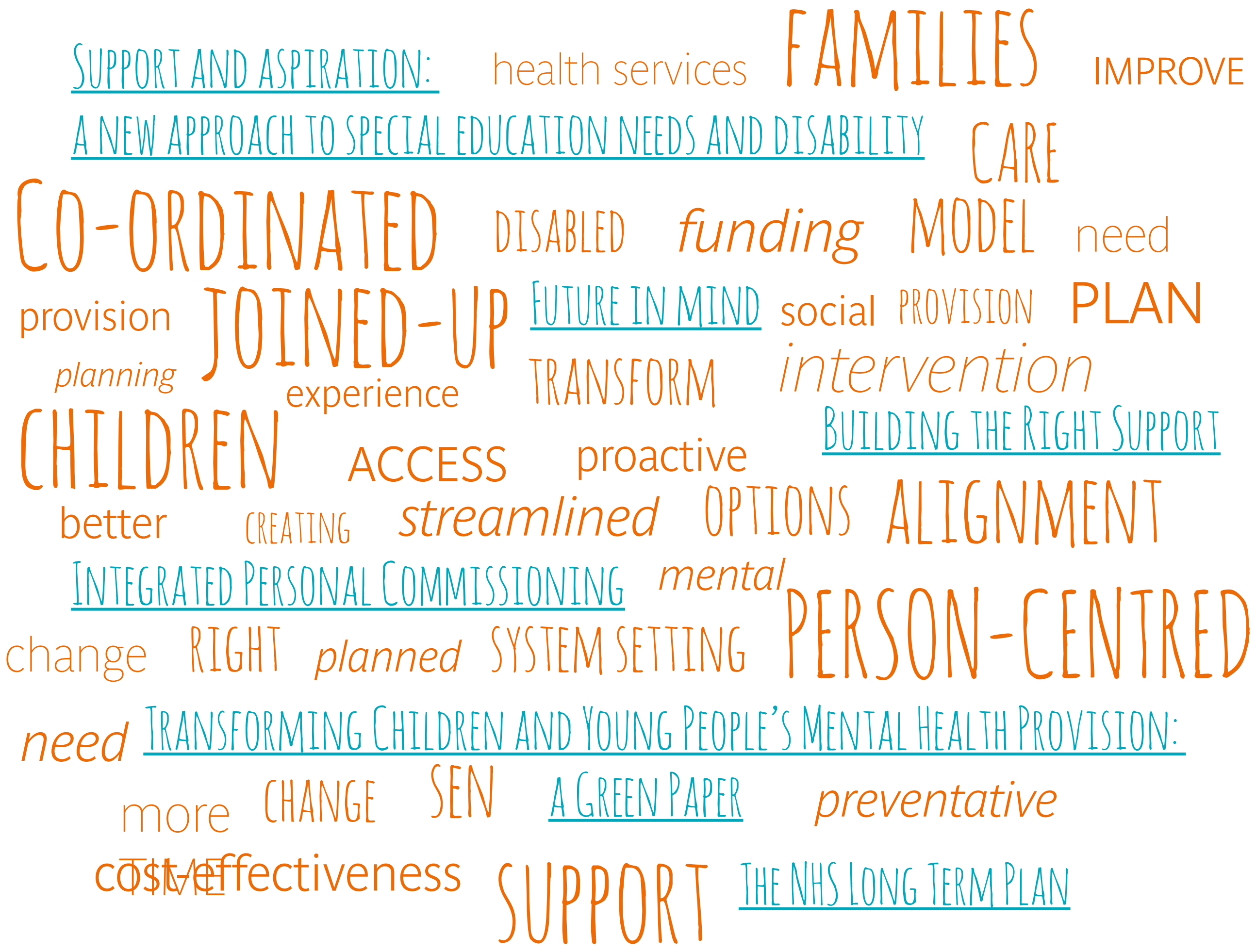
Following consultation with education, health and care professionals and parent carers in three local authority areas, this report considers why the task of integrating the design and delivery of services around SEND is proving so challenging. It also identifies the key factors enabling or hindering progress.

We find that local areas face a significant challenge in overcoming the historical complexity of the system around SEND and traditional siloed focus on specific cohorts or services. The last decade of funding cuts has, for many, made this even more difficult as local agencies turn their focus inwards to protect dwindling resources. We also identify the crucial role of local leadership in uniting services and agencies despite this challenging context, and the importance of good quality data and data-sharing arrangements to support a whole system approach. Finally, we also draw out examples of innovative or promising work happening at local area level that may help others to consider their next steps towards better joint working and integration.

Policy context for integrated services

As previously highlighted, successive transformation programmes and changes in legislation have sought to bring about integrated, person-centred care delivering better outcomes. Activity focussed on improving integration for children and young people with SEND is only a small part of a much wider shift towards integration across the whole health and care system. The Children and Families Act 2014, the Health and Social Care Act 2012 and the Children's Act 2004, all place duties on local authorities and health commissioners to integrate services and improve wellbeing for children and young people.

Figure 1. National change programmes with key words



This should also include any arrangements that make use of Section 75 of the National Health Service Act 2006, including the use of pooled budgets. (Section 75 agreements can include arrangements for pooling resources and delegating certain NHS and local authority health-related functions to the other partner(s) if it would lead to an improvement in the way those functions are exercised.)

In 2014 NHS England published its Five Year Forward View which set out a new direction for the health service, including a greater focus on prevention and early intervention, more personalised care and support and better coordination and integration between different health services and between health and other public services, such as social care. New models of care which would take a different and more integrated approach to structuring and delivering treatment and support were initially adopted and developed by sites around the country, known as 'vanguard' sites. These approaches, where demonstrably successful, have subsequently been reinforced and further developed within the NHS Long Term Plan (2019).

In 2016 health organisations and local authorities in forty-four areas across England came together under Sustainability and Transformation Partnerships (STPs), to map out the needs of their local population and set out plans for meeting those needs in a collaborative, innovative and sustainable way. The aim in the long-term is that all STPs will evolve into Integrated Care Systems (ICSs), whereby partners 'take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve' (NHS England, 2018). At the time of publication, fourteen areas in England had already become ICSs. The Long Term Plan includes a commitment to continue to support the development of ICSs so that they cover the country by April 2021. It further posits a single CCG for each ICS area.

Up until this point the move towards integration has been largely focussed on individuals with the most complex health problems – older adults and those with disabilities and long-term health conditions – whose support needs cross traditional boundaries between health and social care services. Children have generally not been prioritised, possibly because of the added complexity of integrating across education as well as health and social care. Whilst the Long Term Plan promises an integration index to measure 'from patient's, carer's and the public's point of view, the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care' it is unclear whether this is likely to include education services and adequately reflect the experience for all ages.

There are various recognised forms of integrated care (See Table 1) that may help to support those with complex needs, ranging from integration across a specific sector to integration across a particular care pathway.

Table 1. Key forms of integrated care

<table>
<tr><th colspan="5">Integrated care between public health, population-based and patient-centred approaches to health care. This is integrated care at its most ambitious since it focuses on the multiple needs of whole populations, not just to care groups or diseases</th></tr>
<tr><td>Integrated care between health services, social services and other care providers (horizontal integration)</td><td>Integrated care across primary, community, hospital and tertiary care services (vertical integration)</td><td>Integrated care within one sector (e.g. within mental health services through multi-professional teams or networks)</td><td>Integrated care between preventative and curative services</td><td>Integrated care between providers and patients to support shared decision-making and self-management</td></tr>
</table>

Source: adapted from International Journal of Integrated Care, 2016

The policy imperative

Policymakers increasingly recognise the role of wider, external factors in determining our health and wellbeing, and the need to coordinate efforts not only across health and social care but whole 'population health systems' (Alderwick, Ham, & Buck, 2015). Population health is an approach that aims to improve physical and mental health outcomes, promote wellbeing and reduce health inequalities across an entire population. It takes into account the wider determinants of health.

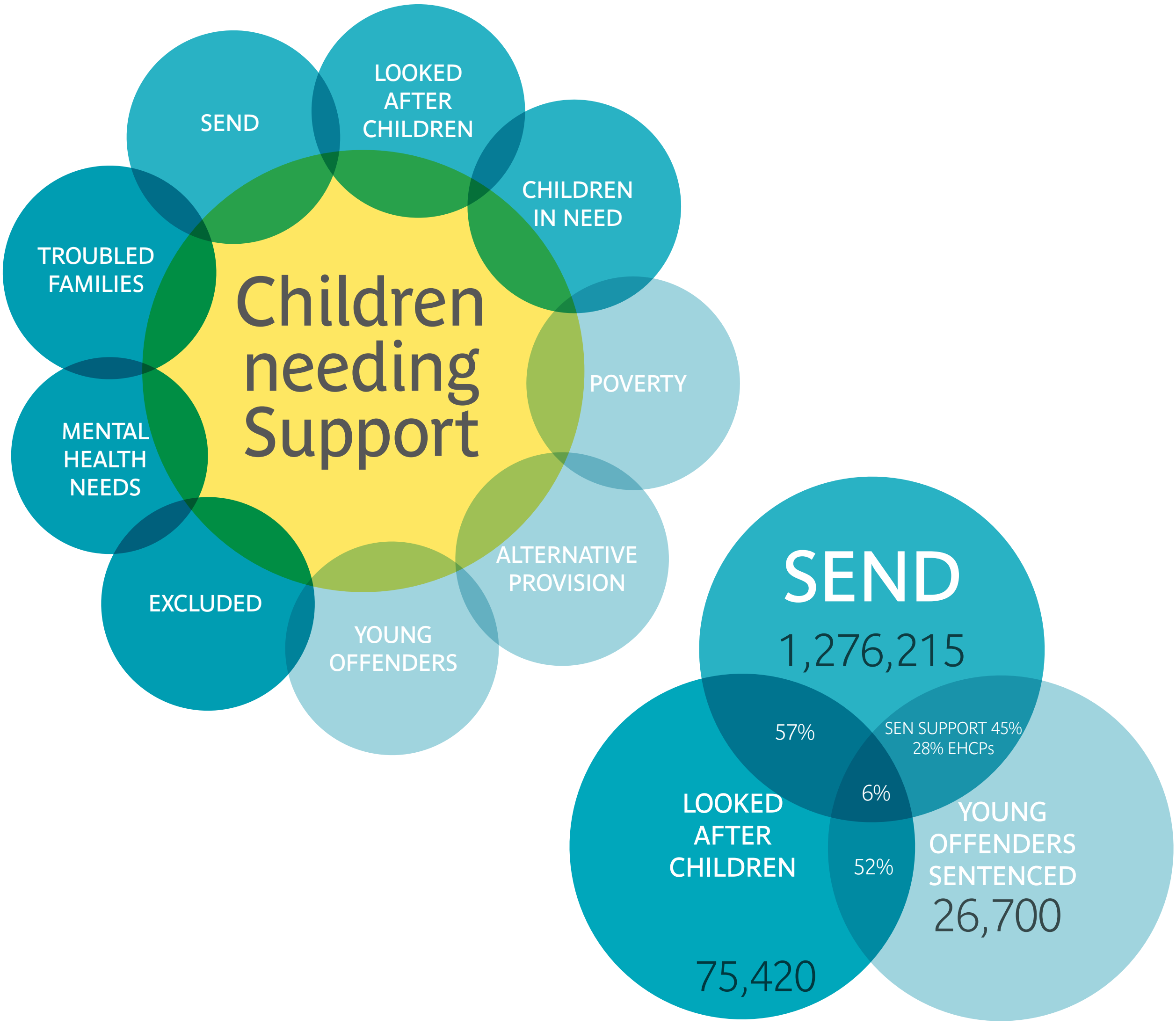
Getting this right for children and young people will be vital to improving population health as a whole. As we know from numerous studies, early life experiences in the womb, home and school are critical to health and wellbeing over the life course (Giesinger, et al., 2014), (Allen, 2011), (Marmot, 2010).

A population health-based approach is also particularly relevant for children and young people with SEND. These children are likely to access a range of services across health, education and social care in relation to their special educational needs (SEN) or disability, but are also more likely to belong to other vulnerable groups; for example they're more likely to live in lower income households, to be in care and to access youth offending services (see Table 1).

A 2018 report by the Children’s Commissioner noted that it is these children, with multiple, overlapping vulnerabilities, for whom existing responses and support arrangements are most likely to be insufficient (Children's Commissioner, 2018). The coordination of public services beyond health and social care to include public health, education and training, youth offending and employment services is therefore likely to make a far more dramatic difference to their health, wellbeing and independence.

The diagram below illustrates the significant overlap between different vulnerable groups and suggests the inefficiency of a siloed service approach. The percentages show the overlaps. For instance, 57% of Looked After Children have SEND.

Figure 2. Overlap between different support needs for children and young people[1]



Complex policy and system structures

Services for children and young people with SEND and their families are organised, delivered and regulated by many different organisations operating at national and local level.

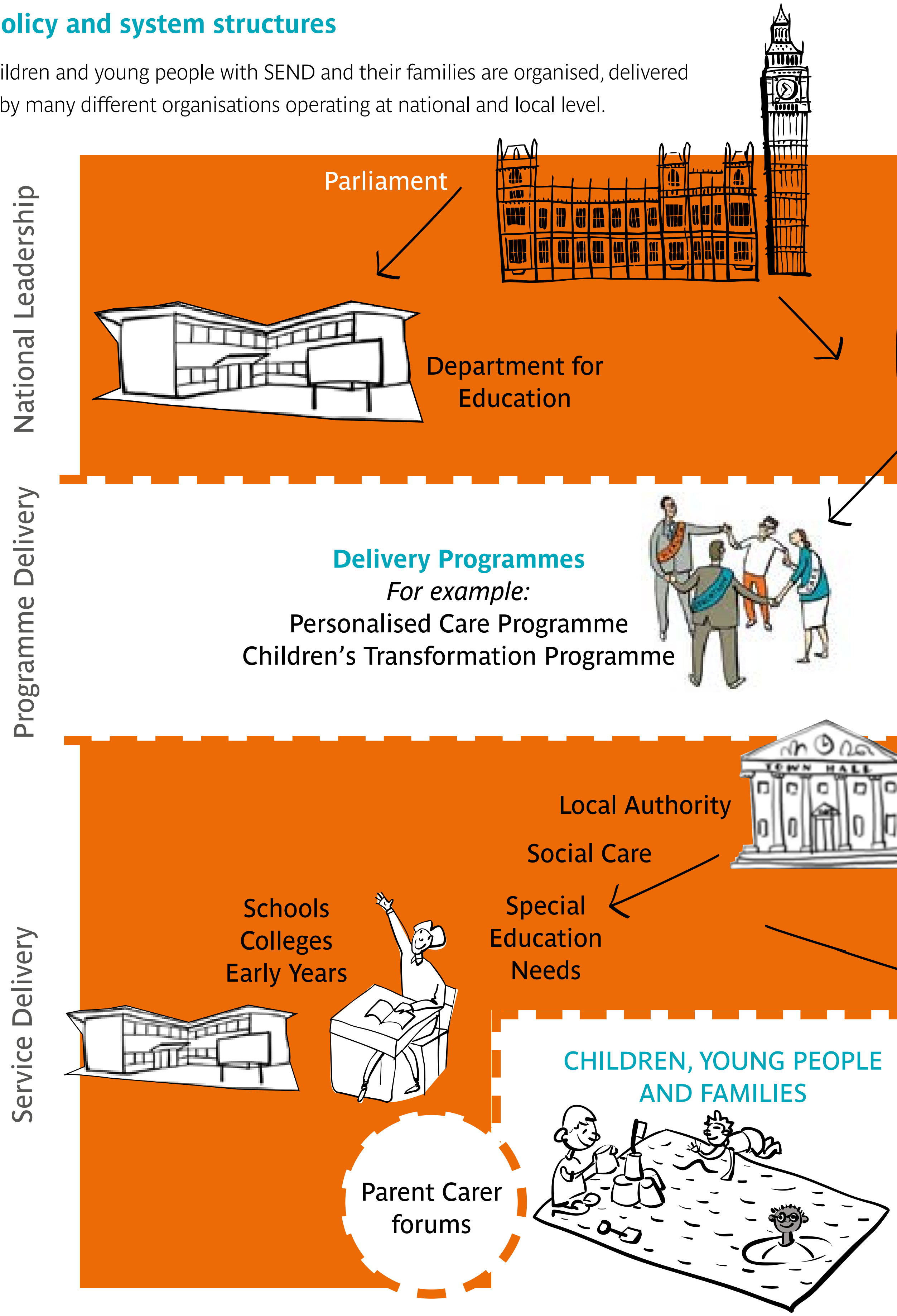


Figure 3. The system around Child Health

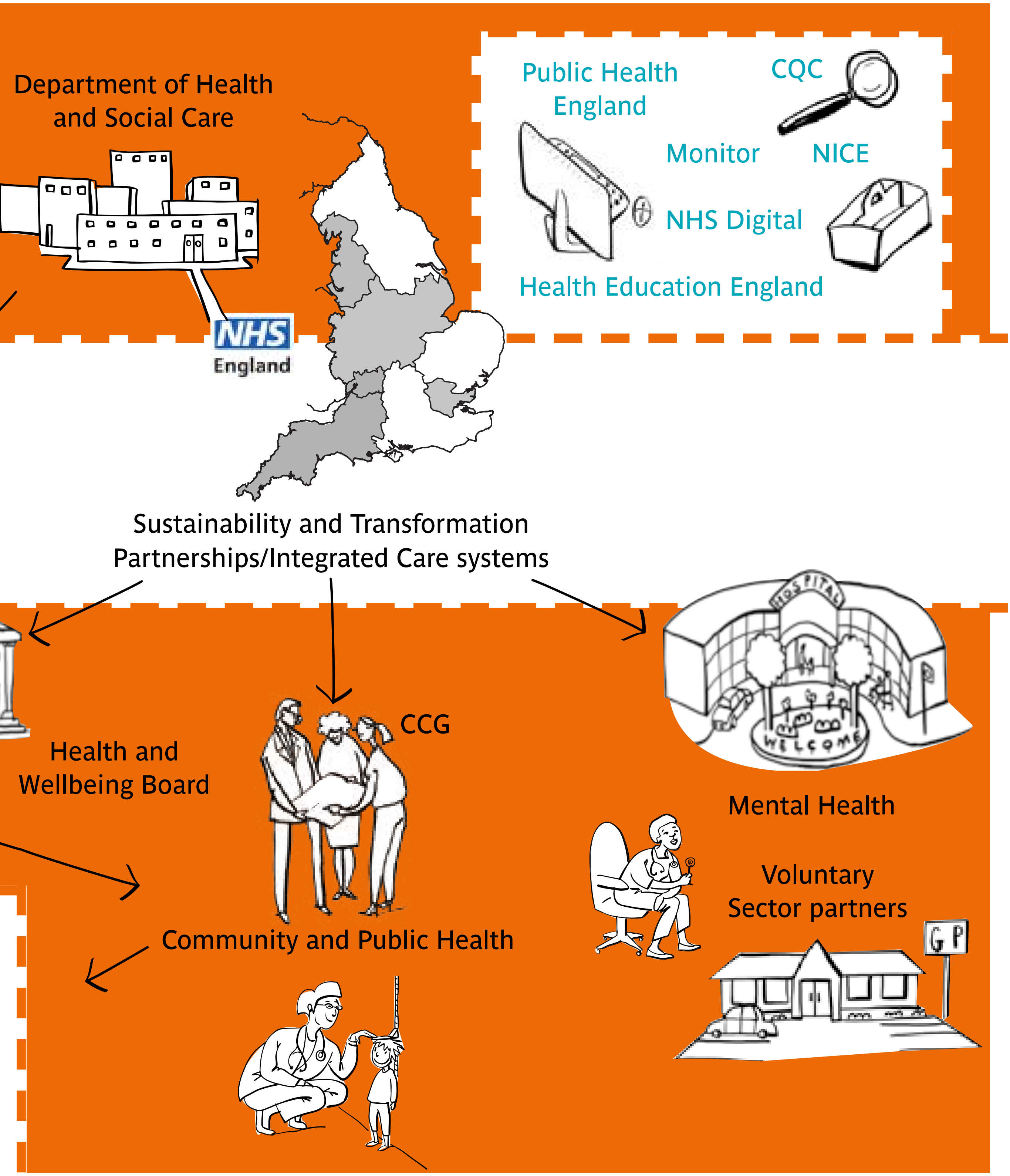


Table 2: Organisations with responsibility for SEND

	Social care	Health	Education
National Responsibility	CHILDREN Department for Education (DfE) ADULT Department of Health and Social Care (DHSC)	DHSC and arm's-length bodies - Care Quality Commission (CQC), NHS Improvement etc. NHS England	DfE and arm's-length bodies - Education and Skills Funding Agency (ESFA), Office for Standards in Education (Ofsted)
Local Responsibility	Local Authority	Clinical Commissioning Group (CCG)	Local Authority, Schools Forum
Providers/ Provision	Social Workers, Short Break Provision, Behavioural Support, Children's Centres, Direct Payments, Child protection, Early Intervention/ Early Help Services	Universal - GPs, School nurses Walk-in centres, NHS Trusts - Specialist Community Services, Paediatricians, Nursing teams and Therapists in Multi-Disciplinary Teams, Child Development Centres, Children and Young People's Mental Health Services (CYPMHS) Short Breaks Specialist Hospital	Education providers - early years, colleges and schools, Special schools, including residential provision, Pupil Referral Units and other alternative provision Special Education Provision - therapies, specialist teachers and equipment
Funding	Children's services are funded by local authorities via the local government finance settlement. Funding also comes from: Council tax - **57p** of every **£1** of council tax income is spent on social care (all ages) (Local Government Association, 2018) Public Health Grant covers some children's services such as early years health visitors	CCG - Funding from NHS England to provide services for local population NHS England - direct commissioning Local Authority - Public health grant	Dedicated Schools Grant - includes national SEN budget – DfE or ESFA Local Authority High needs block from DFE

These organisations are required to work together and coordinate their activity in order to achieve the best outcomes for children and young people. However, they are subject to different legislation, funding models and accountability mechanisms that drive different organisational priorities, as highlighted in Table 2.

This makes the reality of integrated working between different services and agencies, such as NHS and local authority services, children's and adults' services and specialist and universal services, particularly challenging.

Despite a clear mandate from national government, we know from our work with local areas that joint working is not happening consistently across England and in many places is proving a significant challenge. We have heard, anecdotally, a range of explanations for what may be behind this lack of progress – the complexity of existing systems, the impact of funding pressures and of rising demand – as well as numerous examples of good practice, where local leaders have managed to overcome these barriers.

In producing this report we aim to better understand what lies behind this variation by identifying key factors which either enable or hinder local authorities, CCGs and other local partners in their efforts to integrate services for children and young people with SEND and their families.

Our approach

This report is based on research into the organisation and delivery of services for children and young people with SEND in three areas in England, each working within a different geographic and demographic context:

Area A: a large urban area with a unitary local authority and multiple CCGs.
Area B: a medium-sized suburban area with a unitary local authority and co-terminus CCG.
Area C: a large rural area with county local authority and multiple CCGs.

NB: Local areas have been anonymised. This enabled participants to be frank and open about their practice.

In total, we engaged with 74 professionals across all local areas through a mixture of focus groups and telephone interviews. This group was representative of a range of roles across health, social care and special educational needs services including:

- Children's Commissioners for the CCG or for the Local Authority, and one joint commissioner
- Service leads and/or managers for disability/complex needs services/SEN services/CAMHS
- Managers for individual services
- Clinicians and practitioners
- Parent carer representatives.

Information gathered through the focus groups and interviews was then analysed, including using NVivo Framework Analysis software, in order to identify key themes and areas of good practice.

Further details of our methodology are included in the appendix.

Findings

Government policy – a lever and an obstacle

The drive towards integrated working and joint commissioning has very largely come from central government. Participants were very aware of this and in all areas felt that national policy had a significant influence over the choices they made when organising services. Statutory requirements were taken seriously, particularly where they were monitored through reporting to national organisations, or subject to an inspection. For example, the 20 week timescale for the EHC planning process, which is set out in the Children and Families Act, was taken very seriously and treated as a key priority.
“we're monitored on our 20 week deadline… it makes a significant difference to the way I manage my team."

Where national policy provided clear directives and accountability that aligned to local area’s priorities, this was viewed as a helpful enabler for organisations to coordinate their activity. The Children and Families Act was frequently referenced as a national policy change that participants believed was positive and had provided a framework that was supporting local services to come together on an area basis to try and improve outcomes for children and young people with SEND.
***“I think people have seen the benefits… of the EHC plans and have now really bought into the idea that it does improve outcomes and it does help us to focus on the child more, rather than our own services and our agenda.”* Area A**

The Transforming Care Programme was also seen as a positive unifying force in some areas.
***“…the outcomes and what health and social care have to sign up to do [for the Transforming Care Programme], I think are going to be really helpful …it makes people focus on it and gives them a mandate to focus on it, when it may have been a part of their job but now it has to be an absolute focus. They have to go to those meetings, they have to do that piece of work, and it becomes a top priority.”* Area C**

There was understandable frustration expressed about initiatives which have the capability to support integrated working, but do not prioritise children and young people with SEND.
***“…you take the STPs [Sustainability and Transformation Plans], they are the number one thing that we’re all, well, not focused on, but we’re all being led by, and actually if you look at [how little] children and young people feature in them”* Area C**

Additionally, some participants felt pressure to implement successive reforms/policy changes within tight timescales and against a backdrop of stretched resources. Funding cuts risked compromising quality, and distracted from the core principles at the heart of national policy.

"I think the relentless pace of change from the top in terms of legislation is quite a challenge ... And then on top of that, government are constantly changing things around high needs funding and then more... Constantly having to respond to significant pieces of work on a continual basis sometimes feels like you never consolidate, you never get to bed-in, and that bit is quite challenging." ***Area A***

There was also a strong belief, expressed by a number of participants, that the lack of join-up between government departments, particularly the Department for Education and the Department of Health and Social Care and NHS England, in developing and implementing change programmes, hampered inter-agency working at local level.

This is a view supported by the National Audit Office's (NAO) 2017 review of adult health and social care integration which concluded that:

"The Departments' governance and oversight across the range of integration initiatives is poor... The lack of comprehensive governance is leading to uncoordinated effort across central bodies ... The Department of Health has not clarified how the Better Care Fund aligns with the new sustainability and transformation planning process... local government was not involved in the design and development of the NHS-led sustainability and transformation planning process."
National Audit Office, 2017

Areas thought that overcoming these barriers required them to invest additional time and resources in first bringing partners on board around a particular programme and then joining up the work at a local level.

Additional burdens were also created where national operational targets and reporting requirements placed on different agencies and services did not align, making it difficult to identify shared outcomes across the board.

"The tension then comes around national strategies and national legislation that don't appear to be joined up and actually can create tensions locally that we then have to try and resolve. There's different budget streams, different targets, different goals, and there's lots of examples of where, if that had been joined up strategically across, say, Department of Education, Department of Health, key colleagues there... it's obvious, really" ***Area A***

Again these concerns were reflected in the NAO review which identified that implementation programmes created 'significant bureaucracy, which some local areas found was disproportionate and had in some cases disrupted other integration work' (National Audit Office, 2017). Similarly, an Association of Directors of Adult Social Services (ADASS) conference on the vision for health and social care integration found that a short term obstacle to integration was the ‘impact of multiple programmes, e.g. STP, BCF, Pioneers etc...there are too many initiatives, and different priorities for different organisations’. (Rowland, 2016)

All of these concerns are indicative of a short-term approach to integration. Whilst the goal itself may not change, the mechanisms used to drive it forward tend to be funded or monitored for a defined period of time and then a new initiative is launched with slightly different requirements. An international review of enablers and barriers to implementing integrated care suggested that the UK’s efforts to implement integrated care models have suffered ‘due to lack of sustained project management support, restricting such initiatives to short-term projects’ (Maruthappu, Hasan, & Zeltner, 2015). As pointed out over a decade ago by Gill Morgan, former Chief Executive of the NHS Confederation, integration requires a period of stability from reorganisation, as delivering imaginative solutions depends on trust and long-term relationships (Jones, 2011).

Inconsistent government direction

When thinking about integration, participants reflected on the role of universal services in enabling them to provide a holistic, graduated response to children and young people’s emerging needs. They felt that this endeavour was again hampered by a lack of join-up in central government policy; suggesting that the outcomes that universal services were working towards and assessed on did not always enable them to effectively include disabled children and young people.

“...there’s a lot of national policy that impacts on schools around curriculum, attainment measures... All of those things, schools are grappling with that all the time... I sometimes feel that they just they just used it as an excuse ... not to include some children.”

Area C

The lack of support from universal services was felt to bring increasing pressure on specialist services, which lacked the capacity to meet this need.

“[Schools have] got their remit and that’s what they’re focused on... so it can feel very much like separate entities... The knock on is that we have children in special schools that shouldn’t be in special schools.”

Area C

This may be a reflection of the fact that the integration journey began with the join-up between adult health and social care. It has tended to focus on the relationship between the availability of community social care services and delayed discharge from hospital. The picture for children is very different and is more complex; and government policy has paid insufficient attention to this across different work streams. Meaning that, too often, mainstream schools and early-years' settings are not able to meet the needs of children with additional needs who then, as indicated above, move on to more expensive specialist settings.

As an example around 71% of children with autism are educated in mainstream schools, however 60% of teachers in England feel that they have not had adequate training to teach children with autism (Ambitious about Autism, 2013). Exclusions are common, and pupils with an Education, Health and Care plan or a statement of special educational needs are almost six times more likely to receive a fixed period exclusion than pupils with no identified SEN (Department for Education, 2017).

Resourcing issues

INCREASED DEMAND

In every focus group participants felt that demand for services was increasing, due to growing numbers of children with complex needs and increasing complexity of needs. In some specific cases this was based on available figures or an area's own analysis of their local needs, but the lack of robust data on local populations meant this belief was not always underpinned by data.

"We've been saying for years, those of us who've been around this group of young people, there's an increase in complexity because, advances in medicine and what have you… We know that on the ground. But people thought it would plateau, but it hasn't." Area C

However, even where participants did have specific evidence of increasing need, this did not always result in any increase in resources.

"Public Health England did a report on the prevalence, predicted […] that palliative care in [area B] is going to shoot up exponentially […]. So, flagged it up as soon as the report came out. We've included it in our palliative care strategy. We don't have any extra money, just the same." Area B

This perception of an increase in need is borne out by the national data. Recent analysis commissioned by CDC and the True Colours Trust indicate that the numbers of children and young people with complex needs or life-limiting conditions in schools has increased by nearly 50% between 2004 and 2016, from 49,300 to 73,000 children and young people. This figure includes children with profound and multiple learning difficulties, severe learning difficulties, autistic spectrum disorder (special school placements only) and multi-sensory impairments (Pinney, 2017).

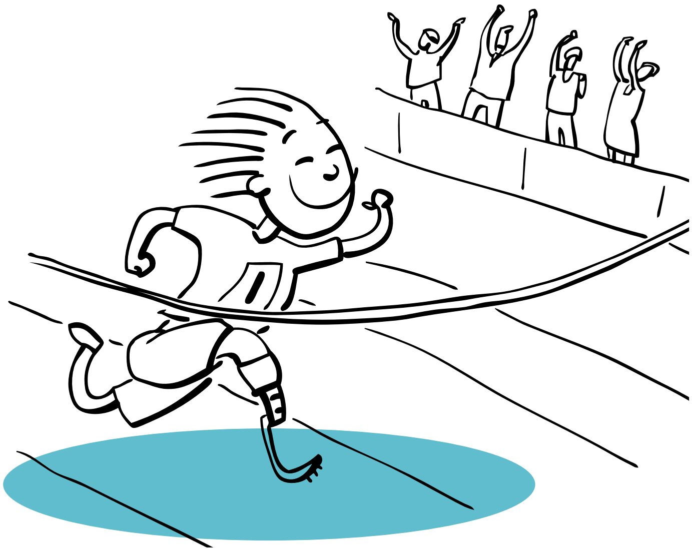
FUNDING CUTS

Resource constraints were a consistent theme in discussions with participants and it is important to acknowledge their level of concern about the impact that reduced resources were having on the quality of the services they felt they were able to deliver. ***"…there isn't enough money in the system to pay for all the care needs, and I'm thinking about children but this also applies in adults as well. And we know, we can see which care companies are going bust or not bidding for local authorities' contracts because it's not viable…" Area A***

It is clear that all of the organisations that support children and young people with SEND and their families are operating within a challenging financial context. A 2018 report by the National Audit Office found that there had been a 49.1% real-terms reduction in government funding for local authorities between 2010/11 and 2017/18, and over two-thirds of local authorities had drawn on their financial reserves in 2016/17 (National Audit Office, 2018).[2]

The Children's Commissioner has recently raised concerns that local authority funding crises could lead to them failing to protect 'services for the most vulnerable children, which could have catastrophic consequences for those children' (Longfield, 2018). Meanwhile, the King's Fund estimates that Clinical Commissioning Groups began 2018/19 with an underlying deficit of £400-£500 million; the forecast end-of-year deficit for provider organisations is £931 million (King's Fund, 2018).

In all areas commissioners and service managers had been required to generate savings by changing the way their services were organised and delivered, sometimes including a reduction in the work force. Austerity had at first generated creativity and in some cases accelerated a drive towards more integrated working; developing joint services to avoid duplication, reduce overheads and improve efficiency.



However, some participants described a process of repeatedly having to restructure services in order to achieve savings. In these cases participants felt the original restructure was based on evidence and led to innovative approaches to maintain or improve services through improving efficiency. The requirement to carry out further restructuring was seen as undermining the results of this process, moving further away from evidence-based decisions and was a significant cause of resentment.

"[When the funding cuts started] initially, yes, we were coming up with creative ideas. There was lots of joint working, people coming in on their days off and things like that, but actually that's been going on for so long now people are exhausted, people are going off on long-term sick because of what's expected of them… goodwill runs out. They're tired. We've shot ourselves in the foot, haven't we because we've kept things going, and they've said, 'right, you've kept things going, great, let's cut a bit more.' …You've got fewer people doing more work…we're all bloody exhausted." ***Area B***

These concerns are echoed in the National Network of Parent Carer Forums' 2018 'State of the Nation' report. The report highlighted tightened local resources as a key issue being raised by parent carer forums across England, including concerns that 'Re-organisations, temporary staff, and frequent changes in personnel have meant that continuity and morale of practitioners is often poor. Embedding the cultural and behavioural changes required by the Children and Families Act against this backdrop is difficult' (National Network of Parent Carer Forums, 2018).

A number of participants explained that joint working and joint commissioning had become more difficult as each partner organisation turned their focus to managing financial pressures. Organisations were focussing on delivering only those services that were underpinned by clear statutory requirements. Such requirements are generally assigned by a single government department, to a single agency; and such a retrenchment must therefore undermine joint working.

"I think there's a real tension in the disability teams, really, about wanting to really embrace everything that's going on in commissioning, in the higher strategic world, and actually the pull to safeguarding, crisis management."
Area C

In two cases joint funding arrangements had broken down.

"We actually had a fantastic service… we probably had one of the best speech and language therapy services delivered five years ago, because it was, a big chunk of funding came from the city council. I don't think the council took that decision easily about taking the funding away for speech and language therapy." ***Area A***

These findings are supported by a scoping research report carried out by SCIE which found that although the current financial climate provides a strong driver for change, local areas found that it meant that some partners had found it hard to sustain their engagement with the integration agenda at the same time as 'dealing with organisational viability – from shrinking budgets and overspends to staff recruitment and retention issues. This has resulted in slowing the pace of change and 'parking' integration activities until a later date' (Social Care Institute for Excellence, 2017).

Such breakdowns in arrangements seems to indicate a lack of commitment at a strategic leadership level to joint working and integrated commissioning; which as we mention earlier, leaves joint working reliant on individual relationships between professionals.

ALLOCATION OF RESOURCES

There appeared to be a particular challenge for participants working with or within health services where the allocation of funding for children's services is often tied up in block contracts and all-age service spending. It is therefore hard for children's commissioners to direct, or indeed, sometimes to distinguish from spending on adults. There was a sense amongst some participants that as a result children were often 'left behind', and did not receive a fair share of health funding.

***"A lot of the decisions that are made, in particular when you're dealing with big organisations such as the health trust ... we're not in full control of money that we allocate . . . wheelchair service I suppose would be a real classic example, that money from children's goes into an all age service, but I have little control about how that money is actually fed to the front line."* Area A**

***"It's harder to deal with big block contracts because you're a subset of a £100 million contract . . . and children in big organisations still get a bit left behind."* Area C**

Concerns about the lack of transparency around funding for children's health services have also been raised at national level by the Office of the Children's Commissioner. A 2018 review of public spending on children stated that researchers had been unable to produce reliable estimates of total health spending for children in all but the most recent years, and could produce no estimates at all for GP expenditure on children. This was found to be "due to the complex organisational structure of the NHS and the fragmented nature of NHS data" (Kelly, Lee, Sibieta, & Waters, 2018).

This lack of transparency also makes it harder for others, including families, to recognise and, if necessary, challenge changes to health spending on children at national or local level. In addition, whilst parents and carers and young people of voting age can express their opposition to local authority funding cuts at election time, there is no clear process for disputing any such changes within health.

The role of leadership

Strategic leadership emerged throughout our research as the single most important factor in enabling or hindering joint working and integration at local level. This was down to local leaders' power to set strategy, influence organisational culture and support initiatives that enable integration.

The importance of strong leadership is also emphasised by the CQC and Ofsted in their 2017 report Local area SEND inspections: One year on. They conclude that, in the most effective local areas, "strong strategic leadership had led to established joint working between education, health and care services" (Local area SEND inspections: one year on, 2017). This in turn was found to have 'underpinned' success in implementing the SEND Code of Practice in those areas.

Conversely, an evaluation of integrated-care pilots in England in 2012 found that 'where a sense of vision was not widespread, progress was noticeably slower, and the barriers cited by staff were greater' (Ling, Brereton, Conklin, Newbould, & Roland, 2012). This finding is also mirrored in our research.

Engagement of local leadership and a shared strategic vision

Participants who felt that senior leaders in their area were engaged with and supportive of the SEND agenda and the move towards integration valued this support highly. Participants largely discussed the engagement of senior management within the local council or CCG/s, although participants in Area A also valued the engagement of political leadership at local level.

"Our political leadership within Area A is very engaged in this agenda… there's been a recent scrutiny report around special education and disability and particularly around transitions and outcomes … And we welcome the scrutiny because obviously it brings fresh eyes to something and asks questions, and that's useful as a driver."
Area A

Those participants who felt supported by senior leaders had a positive impression of how the local area's universal health and wellbeing strategies related to their own work with disabled children and young people and their families, and were, in turn, able to use those strategic plans and priorities to frame their own work in relation to SEND. Participants who felt positive about the influence of strategic leaders were also more confident of receiving support when escalating issues and concerns.

Strategic leadership was felt to be particularly strong in Area A. Participants here frequently referenced their area-wide vision for children and young people which, alongside a range of cross-agency initiatives and governance arrangements, indicated strong senior-level commitment to integration.

"[Area A has] the Children and Young People's Plan, a partnership plan as well, and we've still got a Children and Families Trust Board… So I think it's a really big commitment to that partnership working… We've got a complex needs partnership board that is truly a reflection on the partnership across [area A] from the various different agencies, and that's chaired by our elected member."

Area A

The importance of a strong strategic vision in supporting joint working

A clearly articulated vision from leaders seemed to be particularly helpful for professionals in framing their own attempts to integrate services or agree approaches.

"Because of the clear strategy … it's given us some real value bases that we can collectively work together around… it supports the conversation between what's the health element, what's the care element, what's the education element, because we're coming at it from the same outcome base."

Area A

The importance of strategic leadership and a clear, central vision was identified as a crucial factor for enabling integration in a 2010 evidence review by the Scottish Government which found that for integration to be effective, "the goals driving integration need to be made explicit to all those involved in providing the service" (Weatherly, et al. 2010).

The Children and Families Act mandates such an approach specifying that local partners should identify the outcomes that matter to children and young people with SEN or disabilities to inform the planning and delivery of services.

In Area A, participants spoke about area-wide outcomes articulated in their local area plan for children and young people, which related to the health, wellbeing and quality of life of children and young people. Participants had a clear sense of how these outcomes related to their own areas of work, and used them to inform their own service-level outcomes and priorities.

"we've got a very clear framework … my team plan fits within that … So for us we've got to focus on the quality of education, health and care plan outcomes, looking at the attendance, looking at that, preparation for adulthood and making sure, therefore, that what we do every day is going to make that difference, so that bit for me is quite clear." Area A

Participants from all areas, across all agencies, as well as parents were broadly united around a set of shared outcomes that they wanted to achieve for children and young people. However, in Areas B and C these were based on common understandings of what is important and meaningful for all individuals and families, rather than having been agreed or supported by leadership.

Frequently mentioned outcomes included ‘employment’, ‘quality of life’, ‘friendship groups’, ‘enjoying life’, ‘being part of a community’ and ‘being as independent as possible’. These functioned as guiding principles to influence professional behaviour. However, whilst these informal outcomes may bring professionals together on an individual level they were not formally embedded into service planning or delivery processes and therefore unlikely to prove equally effective in supporting system-wide integration.

Leadership as a barrier to change

In some areas local leaders were felt to be one of the main barriers to a more integrated approach. Their lack of commitment was evidenced by a failure to agree more formal processes for working together. One participant in Area B perceived a lack of senior level commitment as the main barrier to integration and joint working.

“We’ve been looking at integrating our service with our colleagues in the community… this is a project that’s been ongoing for five years and I find it very difficult to get senior management to focus on any change. …That’s very frustrating not just for myself but also for my colleagues and health, you know… I get the sense that people all think it’s a good idea but we’re not high enough on the priority level for it to be actually actioned. There’s always something else more pressing.”
Area B

The detrimental impact of a lack of engagement from senior leadership is reinforced by a study of an integrated-care pathway in Scotland, highlighted in a 2012 evidence review on cross-sector working by the Health Foundation. The study found that whilst staff felt positive about joint working and integration in theory, they were not implementing the pathway in practice due to a lack of integration at, and support from, higher organisational levels (Health Foundation, 2012).

In the absence of such support and with no formal arrangements, the majority of participants referred to good working relationships and shared cultural values as the basis on which services and organisations worked together. In some cases professionals were utilising these informal relationships to circumvent more official mechanisms for joint decision-making.

***"[With the County Council] it's not a strategic connection. It's a sort of, 'I know this person so I can ring them up and talk to them about it'... we're not integrated across agencies and systems but we rely on our individual relationships."* Area C**

***"Where it works well, I think it is that ability to just work together and…just be transparent with issues. It's not about taking sides."* Area C**

However, these informal shared outcomes and cultural values did not always transcend organisational divisions between local authority and health organisations, and between children and young people's services and adult services. A number of participants highlighted perceived differences in the cultural approaches between these services, something they identified as a significant barrier to working together effectively, particularly in Area C.

***"…we're still developing our relationships [with providers] because we're all very different cultures, like education, working for schools, working in the local authority and health, we're all different beasts, really, and so that's the developing relationship."* Area C**

These barriers could not always be overcome through the development of individual relationships, and even where they could be there was a recognition that this was not sustainable in the long-term.

***"It's different on the individual level than it is on the systems level. I guess the struggle there is, if you lose those individuals, if they're not on the ground, if people leave…it's not something you can rebuild on. We'd lose that [connection]."* Area C**

It was clear from the professionals we spoke to that the lack of formal processes agreed at a senior leadership level placed significant additional time burdens on them as they got caught up in agreeing packages of care.
"When we have things like special arrangements in school then we will actually do a, for want of a better word, wrangling conversation with; health can support, say, the escort on transport, so they will fund the cost of the training for the escort on the transport and education will fund the cost of the escort themselves...but we do have to revisit every single child and look at what are the needs of those, of that child, [what] are the agreements... that we've already got going to meet the needs of that child..." Area B

"I sometimes get involved in discussions with other commissioners, whether a piece of equipment or a particular adaptation is a health need, in inverted commas, or an education need and who's going to pay for it... that doesn't feel like a helpful way of doing business ... it would be useful if there was something more strategic to say, actually it's obviously a health, education, social care need because it's about this child's life... their benefit from that particular piece of equipment isn't going to stop when they leave the classroom and it's not going to just be with them at home. So how do we all work together in a way that means that the family aren't having to wait whilst we make those decisions?" Area C

Without a strategic-level commitment to joint working, and against a backdrop of sustained cuts to public funding, accepting responsibility for funding elements of care clearly felt like a risk for some professionals.
"As a commissioner you're thinking if I make a decision for this one person, am I setting a precedent and next time something similar happens or the next ten children, that something similar happens, am I going to be expected to fund [this again]... it shouldn't be happening like that. It should be more of a whole systems approach." Area C

It is encouraging that the NHS Long Term Plan envisages greater collaboration and a process of system oversight that ensures that neither trusts nor CCGs will pursue actions which, whilst potentially improving their institutional financial position, would result in a worse position for the system overall. However, things may not improve for children and their families if this greater collaboration and oversight does not also include local authority services, including education.

Data and information-sharing

At a strategic level, better quality population data should support areas to look at the 'big picture', identify gaps and pressure points, respond together as a system and develop a shared strategic vision with clear and consistent leadership; delivering services in an integrated way for the benefit of the whole population.

At individual level, better data and information-sharing can allow professionals timely access to the data they need in order to give the right advice and support to a particular child or young person and their family. This also makes it easier for professionals to work together to coordinate support packages and plan ahead for transitions.

Assessing need

Participants were generally dissatisfied with the availability, quality and compatibility of local population-level data and its usefulness in assessing levels of need.

***"[We] had really weird statistics from the school census on autism. The school census data indicated that we had extremely low rate of autism in Area A, which didn't feel right, but we in health couldn't run any reports on that because diagnostic data is all written in individual's records, there is no way to run a report on it."* Area A**

***"I don't know if there is good quality population data out there… I've been asked to look at what resources would be needed to meet the gaps in how we meet the ASD [Autism Spectrum Disorder] NICE [National Institute for Health and Care Excellence] guidelines. But I'm not sure how to do that because I don't know what children are out there and what their needs are."* Area B**

This is not only a local, but a national issue. A 2017 report by the Council for Disabled Children and True Colours Trust, identified a clear need for better quality population-level data to support local areas to understand needs and to plan ahead more effectively (Pinney, 2017).

Even where participants did have access to good quality population data, this did not necessarily lead to a more holistic understanding of local need or more integrated working. Instead, participants spoke about using evidence of increased need to bid for more resources or protect funding for specific services or cohorts of children (although this approach was not always successful).

"I think local authority data is very good, actually. So, for example, I was able to show that our percentage of children with the most complex needs, i.e. those with statements and plans, has increased by 50% over the last five years. ...[as a result, ours] was the only department in the whole of the council that made a successful growth bid for staff last year." (Area B)

This use of population-level data, when available, to support existing, siloed ways of working is possibly unsurprising in the context of tight budget constraints and in the absence of strategic leadership-support for a more integrated approach.

Measuring progress

Participants were comfortable using data to measure their progress against narrow, service-specific targets. However, even where local areas had defined a clear set of outcomes for children and young people with SEND, tracking their success in achieving these wider, multi-agency outcomes, both at individual and population level, was a significant challenge for all participants.

"...it's hard, isn't it...how do you measure when you've had a positive contribution, that you maybe helped to prevent ... something deteriorate, that's where we always struggle, to start to measure that." Area A

Participants were clear that the lack of a joined-up government approach to data made measuring progress and outcomes in a meaningful way more challenging. Data collected by NHS England, the Department of Health and Social Care and the Department for Education generally relates to outputs or outcomes from a particular service intervention. They do not adequately reflect the drive towards integration or the focus on child-centred outcomes introduced by the Children and Families Act. This means that where local areas are collecting data to measure improvements in these areas they are adding to their data-gathering burden.

"I think most authorities tend to gather information that is required by government in returns which often are a very long way from the underlying principles of what government say they're trying to achieve." Area C

Despite the additional effort required, all local areas were investing time and resources in developing ways to overcome these challenges and measure improvements in children's outcomes in a robust way. Participants in Area A spoke about local efforts to develop an effective outcomes measure based on the Canadian Occupational Performance Measure (Canadian Occupational Performance Measure Website, 2019) whereby children and families set their own goals or outcomes and assess their satisfaction or progress against these over time. The aim was that these individual outcomes could then be linked to strategic, multi-agency outcomes to build up a picture of progress area-wide.

"...from a commissioning standpoint ... the two golden things are a qualitative and a quantitative measure because we need to count widgets, because we need to assure people the money that we spend on behalf of the public is spent in the wisest possible way, but just as importantly, if not more importantly, is that that money reflects what people truly want." Area A

Given that data collection is time consuming, whilst local areas understand its importance, it is unlikely that the collection of data needed to support the case for integration will be prioritised, if it is not either required by local leaders or a centrally mandated requirement.

Individual-level data and information sharing processes

Participants in all areas also recognised that good information sharing processes, which enable different organisations to share information relating to individual children and young people, are a key enabling factor for effective joint-working and integrated care. However, information sharing between different services and agencies was proving particularly difficult in all areas due to data being held in multiple places, incompatible IT systems and differing governance and security arrangements between agencies.

"if you have a child who has joint health and social care, education needs, you can't easily share data across the board in some cases because we're all on different systems, we've got different levels of governance, we've got different levels of security, which makes it very difficult to have a conversation with someone outside your own organisation about a child." Area C

Of all the groups, Area A participants were the most positive about their area's local processes for information sharing. In particular they valued being able to see a record of the care or treatment a young person had received across services and agencies, in the same format.

"There's also the Care Record which is relatively new, another really useful thing, making it a lot easier, tells you when young people have had contact with medical services, when they've been in hospital and they've had blood tests back, and that's just really helpful." Area A

However, participants acknowledged that establishing these processes had been, a complex and difficult task.

Data-sharing arrangements were also in place in Area C. However, these were not felt to be particularly successful; in part, it seemed because of the impact of a failure to co-produce a joint solution across all agencies.

"...when the trust got their shiny new customer information system, it became a lot of pressure to start putting things on that, and because the county council

hadn't and didn't take it as high priority to make that system enable our health partners to pull out some of their performance information... If you are going for a single thing it has to be ... co designed by the organisations ...to make sure it will do what each needs it to do" Area C

For some participants, low levels of commitment to maintaining shared datasets linked back to challenges around leadership and the failure to prioritise children's services.
"And we've just started, I've forgotten what it's called because it's quite new, this whole dataset for community services, feeding in, and when I looked at it I noticed our trust hadn't put in the data, so I was feeding up to them saying, but, of course, they're thinking all the adult services" Area C

A lack of formal processes also increases pressure on parents to coordinate information-sharing between the different professionals involved in their child's support.
"To be honest, the best solution I've seen so far is that highly motivated proactive parents actually keep all the data on their own iPad and bring it to every appointment." Area B

For information-sharing processes to be effective there therefore needs to be a system-wide governance approach to data-sharing across organisations, and system processes to enable appropriate data to be identified and shared with the right people at the appropriate time. This needs to take into account both concerns about different requirements for data-sharing and data confidentiality and the barriers created by the use of incompatible IT systems. The support of senior leadership will also be a factor in ensuring adherence to any processes that are put in place.

Making it work

Despite the challenges presented by the system, there are a number of ways in which local areas are working to overcome this complexity and enable some level of integration.

As referenced in the introduction, there are various forms and levels of integration. Care can be integrated around the individual, across multiple services or system-wide; it may be low level - introducing improved referral-pathways and information-sharing processes between two teams - or as high level as formally merging multiple organisations.

We have come across various initiatives and arrangements both through this research and in our work with local areas across England. In all cases, they appear to work best where they are supported by senior leadership and a clear strategic vision.

Commissioning arrangements

At systems-level, organisations can come together to jointly plan and deliver services through joint-commissioning agreements, outcomes-based commissioning or other innovative commissioning arrangements.

Effective joint commissioning arrangements have been recognised throughout the local area SEND inspections as enabling better coordination of services and improved outcomes for children and young people.

> ***"Excellent joint commissioning arrangements between education, health, and care services is leading to a better coordination of services for children and young people who have special educational needs and/or disabilities and their families."***
> ***Local area SEND inspection letter for Southampton, March 2017***

Joint commissioning arrangements may be made for an individual post, a specific service or a full integrated pathway.

Commissioners are increasingly coming together to jointly commission roles which support joint working – most notably the Designated Clinical Officer for SEND role (DCO). Where jointly commissioned, DCO roles may be funded by multiple CCGs, the local authority and CCG or, in some cases, by different organisations across multiple local areas. The DCO role is recognised as having a key role to play in joint working and joint commissioning arrangements, as highlighted in inspection reports and Local area SEND inspections: one year on and this strength is likely to be amplified where the role is jointly-commissioned. However, inspectors also acknowledge that to be truly effective these roles must have the support and oversight of senior leadership (Local area SEND inspections: one year on, 2017). Where posts are jointly commissioned this support must come from all commissioning bodies.

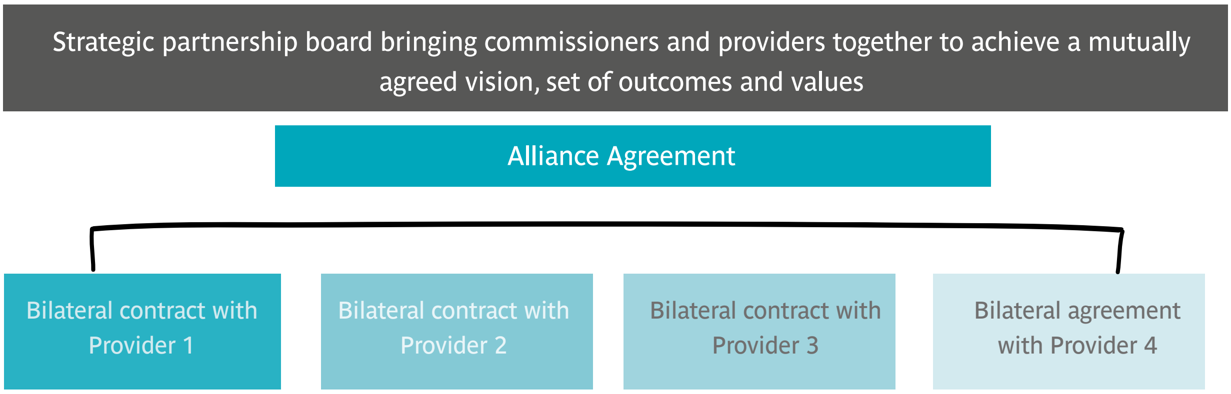
Local authorities and NHS bodies can make formal arrangements for sharing resources and responsibilities for health related functions under Section 75 of the National Health Services Act 2006. Participants in Area B found that the formal Section 75 Agreement in place in their area had made it harder to 'walk away' from joint working responsibilities, and therefore increased local commitment to integration.

***"The [formal processes and responsibilities for joint working] does mean it's a bit harder to get out of it, so if you're just informally collaborating you can sort of… walk away from that, but if we take the Section 75 to bits, that's going to be a big, old process in terms of governance and decisions and all the rest, so in that sense it probably slows disintegration down a little bit because it, you have to do something to break it up."* Area B**

Commissioners can also support joint working through adopting an Outcomes-Based Commissioning (OBA™) approach, engaging multiple providers with delivering on the same key outcomes. Leeds City Council used the OBA™ approach to great effect following a 2009 Ofsted inspection which found that the council did not adequately safeguard vulnerable children and young people. The council identified four key population indicators and applied the three OBA™ performance measures – *How much did we do? How well did we do it? Is anybody better off?* – across all services. By 2015 the city had seen a significant change in outcomes for children and services for vulnerable children were rated 'good' by Ofsted (Friedman, 2015).

There are a number of innovative contracting models that can support outcomes-based commissioning, such as Alliance Agreements, whereby different providers who already have a contract with a commissioner are brought together to work towards shared outcomes for a specific population. This model encourages providers and commissioners to work collaboratively.

Figure 4. Alliance agreement contracting model



Camden's Integrated Children's Service is a formal partnership between the local authority and four health providers, all of whom manage separate budgets and employ different professional teams. They are brought together through an Alliance Agreement which holds all partners to deliver against the same five key performance measures, and lead professionals from each organisation meet regularly to ensure work is aligned. They are further incentivised to work collaboratively by a performance-related pay model, whereby if all partners meet the agreed targets the services receive additional funding.[3]

Another model is the Accountable Provider Model or Prime Contractor Model, in which one provider is commissioned to deliver an integrated pathway of services designed to achieve a defined set of outcomes. This usually involves subcontracting other providers to support different elements of the programme/service. Subcontractors are held to achieving the same defined outcomes. The NHS Long Term Plan announced that NHS England would make an Integrated Care Provider (ICP) contract available for use from 2019.

Joint working arrangements

Joint working arrangements, whereby two or more teams or agencies agree to work together around one or more issues, can range from informal agreements, perhaps bound by a Memorandum of Understanding (MOU), to formal partnership agreements and the contracting models described above.

Participants in Area B reflected on their experiences of working in integrated teams and of co-location (sharing office space with another team). They felt that such approaches improved their ability to work together with colleagues from different services and agencies.

"It's a shared building [that's] owned by the local authority… So there's three services from the Partnership [ ] Trust… Then we've got the speech therapy team… there's physios, who are employed by the local Hospital… Then we've got paediatricians who are based here. And then we have visiting clinics, so audiology, ophthalmology, different types of people who come in. So they all use the building. And then attached to the building we have a local authority nursery… We've been here a few years now, but where we used to be based, it wasn't as easy to work in a multidisciplinary way, so that's been a good thing." ***Area B***

A set of case studies by the Social Care Institute for Excellence (SCIE) has highlighted the value of multi-disciplinary teams in driving integration. SCIE stresses that there are different ways of doing this, ranging from formal arrangements, where teams are brought together under a partnership body, to the introduction of systems and processes that enable professionals across different organisations to come together to manage complex cases. Teams may or may not be co-located, but are commonly united under shared processes and records systems, joint meetings and an identified manager or practice leader who oversees and facilitates the team's work. Another common feature is the **'key worker'** system whereby care is coordinated by a named worker. As with other initiatives, these teams are empowered by the support of senior leadership: "bodies overseeing this area of collaboration must provide support. This should include pubic endorsement (and so legitimacy), ensuring that the MDT has the necessary resources, and developing integrated performance systems" (Social Care Institute for Excellence, 2018).

Participants also spoke about the benefits of having formal multi-agency decision-making processes in place. These should enable different partners, for example from the local CCG and local authority, to navigate the differing referral processes, threshold criteria, delivery models and funding mechanisms in order to agree on and deliver an appropriate package of support for a family.

For a number of participants, multi-agency decision-making "panel" processes played a significant role in decision-making processes. These panels were made up of representatives from different local agencies responsible for SEND, and were most effective where those representatives had the discretion to make decisions which impacted service delivery and resource allocation. In successful examples, panel representatives were also usually supported by clear, multi-agency arrangements and processes agreed at strategic level.

"...on our continuing healthcare panel, which is a multi-agency panel, there are pre-agreed funding arrangements. So, for example, if a child with complex healthcare has to have surgery for whatever reason then health and social care have an agreement that for six weeks post operatively they will split 50/50, regardless of the cost, 50/50 the cost of the personal care for six weeks."
Area B

It is important to note that without clear decision-making powers panels are ineffective, time consuming and therefore costly, and may cause even more frustration for families and professionals alike.

"I think it is extremely frustrating when you're agreeing, you've got different panels agreeing packages of care, and you don't necessarily have the wherewithal to then deliver it."
Area B

Without delegated authority and a clear framework from senior leaders, committed to joint working, panels become a 'wrangling' arena where professionals can lose sight of the needs of the child and family in their efforts to protect their own agency.

Involving families in decision-making

Effective processes for involving families in decision-making also support integration at an individual level by uniting professionals around holistic ambitions and outcomes. This should also be true at a strategic level, where effective participation and co-production should have the effect of uniting different agencies around what matters to families.

Participants recognised the value of putting the voice of children, young people and their families at the heart of not only individual care plans, but also area plans and strategies, particularly those which multiple agencies were involved in delivering. They described a range of processes used in their areas to gain children's, young people's and parents' and carers' views.

Strategic co-production with parent carers was achieved by involving families from the earliest stages through workshops, meetings, consultations and representation on programme boards. Parent carers were also involved in day-to-day work through representation on multi-agency panels or governance boards.

Involving children and young people at strategic level was felt to be more challenging, but all areas were making efforts to include young people in these processes too, or to seek their advice through workshops and engagement groups.

In our other work we have come across some excellent example of co-production. For example, in Hertfordshire, parent carers and young people were closely involved in developing the cross-agency Outcome Bees, a set of six outcomes which all agencies want to achieve for children and young people, and which will be used to inform service-planning.

Figure 5. Hertfordshire's Outcome Bees for all children and young people

Some local areas have established Young Commissioners groups to support commissioning and procurement activities, undertake research and make recommendations about services from a young person's perspective. The Royal Borough of Greenwich's Young Commissioners programme was highlighted in their inspection report as one of a range of effective strategies for gaining the views and input of young people in strategic-level decision-making: "Inspectors learned of a range of services and support which was working better because a range of views had been considered. For example, young commissioners have designed the questionnaire for interviews held when a young person returns home after going missing" (Local area SEND Inspection letter for the Royal Borough of Greenwich, August 2017).

However, in all areas participants had mixed views on the effectiveness of their own local processes for engaging with children and young people and parents and carers in strategic-level decision-making. In particular, they were not always confident that the information gathered from children and young people was used effectively or consistently to influence and coordinate the design and delivery of services.

"I think I've been to a number of workshops where there have been parents represented, young people represented, and there's always a lot of hope and optimism about this is what we want things to look like, but [Area A] is huge and there's so many little services, and trying to get the ball rolling and connecting things up and trying to get towards that vision is just so tricky."
Area A

Engagement with families must therefore be meaningful, with a clear, pre-determined process for feeding any outputs into strategic planning. This again links to leadership and strategic-level commitment to change.

At individual level, integration can be supported through building dedicated time and space for a person-centred conversation, with the child or young person and their family, into support planning processes. Then ensuring this conversation informs the rest of the process and any resulting support package, thus uniting agencies around holistic needs, outcomes and aspirations. Given significant pressures on staff time and resources this may sound difficult to achieve. However, some areas are thinking creatively in order to do this, for example by reinstating a **'key worker' role**. In the integrated learning disability service in Portsmouth all team members – whether nurses, social workers or therapists – have a case load, and carry out person-centred planning conversations.

Whilst families very much welcome a key worker approach there may be a question whether this approach shifts the burden of responsibility for integrating services from leaders onto front line practitioners; and, where there is no key worker, onto parents themselves.

This then raises concerns over the equity of care: some of our participants worried that those children whose parents or carers lack the skills, confidence and knowledge to act as effective coordinators may lose out on the best support. Formal processes, such as those discussed here, are therefore essential to harness the knowledge and skills of parents in a meaningful and equitable way in supporting their children's care. In addition, the effective engagement of parents and carers must be one of a range of strategies for supporting the integration of care at individual level, and cannot substitute broader efforts to join up services.

Appendix: Methodology

Recruitment

The opportunity to be involved in this research was promoted through CDC's existing networks, following which three areas were selected to take part. A key factor in the selection process was the need to reflect differences in demography and governing and commissioning structures across the country.

We received interest from professionals in NHS and Local Authority services in thirteen local areas. We followed up these thirteen areas with information about the project, what would be involved in taking part, and asked them to provide information about their area and secure buy in from the key stakeholders in their area. At this point several areas decided not to participate in the project due to internal pressures and competing priorities which meant that staff were not able to contribute their time.

Process for agreeing local delivery with participating sites

The process of securing local area participation and involvement of key stakeholders was more complex and time-consuming than originally anticipated. This was a result of the tripartite service structures that we wanted to investigate meaning that there was a process of identifying and securing buy-in from professionals across local authority, social care and health in each area. This was a multi-stage process, negotiating existing relationships between organisations within sites. Of the three areas we initially identified and engaged with, one was ultimately unable to participate (Area X), and a fourth area needed to be identified to take its place (Area C).

The process of securing agreement at the required levels within different organisations reflected the differing organisational priorities, resource pressures and relationships that became a key focus of this research.

Summary of engagement activity

Area A:

- Initial interest from the NHS Provider clinical lead (June 2016).

- Follow up emails between NHS provider and CCG (Clinical Commissioning Group) to establish basis of participation; highlighted relationship issues.

- Email and telephone discussion followed up with two meetings in September 2016 with CCG commissioning lead and Clinical Lead in Provider Trust.

- Buy in from local authority SEN team secured through email based on existing relationship.

- Presentation to thirty professionals in complex-needs team on participation in the project; agreement secured (November 2016).

- Activity postponed until May 2017 due to Ofsted CQC inspection announcement.

- Administrative support from community health team designated to support deliver of sessions.

Area B:
- Initial interest (June 2016) expressed by joint commissioning lead for complex needs across Local Authority and CCG.

- Meeting with joint commissioning lead, local authority service manager and parent carer representative to present on project and agree participation (September 2016).

- Preliminary meeting with joint commissioner representatives from local authority, and leads from provider trust to plan delivery; postponed to February due to key staff availability.

- Agreed local delivery plan, joint commissioner lead contacted (February 2017).

Area X:
- Initial interest from Designated Clinical Officer within community provider and CCG (June 2016).

- Meeting with CCG and local authority to explain project and plan delivery. Agreement in principle (September 2016).

- Presentation to complex-needs group, including professionals and elected council members; significant issues raised by elected lead members on board regarding participation (October 2016).

- Formal submission to council members required with rationale for participation; decision made not to participate. Factors in this decision included the recent negative Ofsted CQC inspection letter and financial/political situation (December 2016).

Contingency Recruitment – Area C:
- Due to difficulties in securing agreement with identified areas (notably area X) a second recruitment email was sent out to colleagues in local areas who had participated in CDC's Social Care Innovation Fund programme in December (2016)

- We received a positive Response from Area C, followed by call with joint commissioner and local authority manager to agree participation (January 2017).

Desk research into local areas

Prior to the workshops the project team undertook a review of each area's strategies and operational plans relating to children health, education and social care services. This focused on identifying relevant outcomes and structural processes to understand local context and develop a framework from which to understand focus group findings.

Focus groups

Following the review of available information we held five focus groups with 35 professionals, and telephone interviews with 39 professionals across health, social care and special educational needs services including:

- Children's Commissioners for the CCG or for the Local Authority, and one joint commissioner;

- Service leads and/or managers for disability/complex needs services/SEN services/CAMHS;

- Managers for individual services;
- Clinicians and practitioners;
- Parent carer representatives.

Two focus group sessions were delivered in each area with the exception of Area C, where there was an initial focus group but the follow up was conducted via telephone interviews as the area was not able to release staff concurrently to attend a focus group.

Key issues identified from the evidence review were translated into questions and activities to generate discussion on key topics in a detailed two-hour topic guide.

STRUCTURE OF FOCUS GROUPS

Focus group sessions were structured around three stages of inquiry:

- Stage 1- Understanding the outcomes that partners in each area are trying to achieve for children and young people with complex needs

- Stage 2- Exploring what factors enable and inhibit local services from organising and delivering services effectively to improve outcomes for children and young people with complex needs

- Stage 3- Exploring the positive and negative impact of national factors in influencing local areas in their decision-making.

POST FOCUS GROUP ANALYSIS

Recording of sessions were transcribed and transcripts analysed using NVivo Framework Analysis software. This approach supports the identification of inter-relationships between key themes, in addition to highlighting good practice.

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Endnotes

1. Current figures for LAC, children with SEND and children in custody
- The number of pupils with (SEN) was 1,276,215 in January 2018 (DfE, Special Educational Needs in England, 2018)
- At 31 March 2018 there were 75,420 looked after Children (DfE, Children Looked After in England, 2018)
- In 2017/2018 26,700 children and young people were cautioned or sentenced in court (Youth Justice Board/MoJ, Youth Justice Statistics 2017/18)

Intersection between vulnerabilities
- 57.3% of LAC have a SEN identified by the end of KS2 (DfE, Children Looked After in England, 2017)
- 52%* of young offenders asked for a 2014-15 study said they were or had been in care (Youth Justice Board, Children in Custody 2014–15, 2015)
- 45% of young offenders sentenced in 2014 at the end of KS4 were recorded as having SEN without a statement, and 28% as having SEN with a statement (DfE and MoJ, Understanding the educational background of young offenders, 2016)
- 26% of boys held in YOIs in 2014-15 who said they had been in local authority care also reported having a disability (Youth Justice Board, Children in Custody 2014–15, 2015)

*This is the percentage who said they were or had ever been in care. The official figures are much lower and only represent children currently looked after.

**Prevalence rates of neurodevelopmental disorders among young people in custody (Howard League What is Justice? Working Papers 17/2015)

2. National Audit Office, Financial sustainability of local authorities 2018 (March 2018)
3. To read more about Camden's model see the case study on the Council for Disabled Children's website: https://councilfordisabledchildren.org.uk/help-resources/resources/case-study-integrating-childrens-services-camden

Report design linkedin.com/in/annemetcalfe

Illustrations goatpix.com

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector with a membership of over 200 voluntary and community organisations and an active network of practitioners and policy-makers that spans education, health and social care. Their aim is to see a fully-inclusive society where disabled children and young people and those with special educational needs can lead full and happy childhoods and rewarding adult lives. They do this by working with the sector to find out what is and isn't working on the ground and use what they learn to influence policy and improve practice.

CDC hosts the following networks and projects:

Early Years SEND Partnership
IASS Network
Making Ourselves Heard
Special Educational Consortium
The Information, Advice and Support Programme
Transition Information Network

CDC is proud to be part of the National Children's Bureau (NCB), a leading children's charity working to build a better childhood for every child.

More information about CDC can be found at www.councilfordisabledchildren.org.uk

About the True Colours Trust

The True Colours Trust is passionate about making a difference to the lives of disabled children and their families and supporting people with life-limiting and/or life-threatening illnesses. The Trust was established in 2001 and works in the UK and Africa.

True Colours has developed a framework of grant-making which enables it to effect change in the short, medium and long-term. This is done through small grants to local initiatives; multi-year grants to build sustainable organisations and sectors; commissioning research to gather information and identify solutions to complex issues; and, making long-term investments towards advocacy and policy change. The Trust's framework enables it to make positive change today, tomorrow and in the future. The Trust is proud to be a long-term supporter of the work of the Council for Disabled Children.

More information about the True Colours Trust can be found at www.truecolourstrust.org.uk