

It takes leaders to break down siloes

INTEGRATING SERVICES FOR DISABLED CHILDREN

Executive Summary

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Introduction

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, the system around SEND remains fragmented.

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.

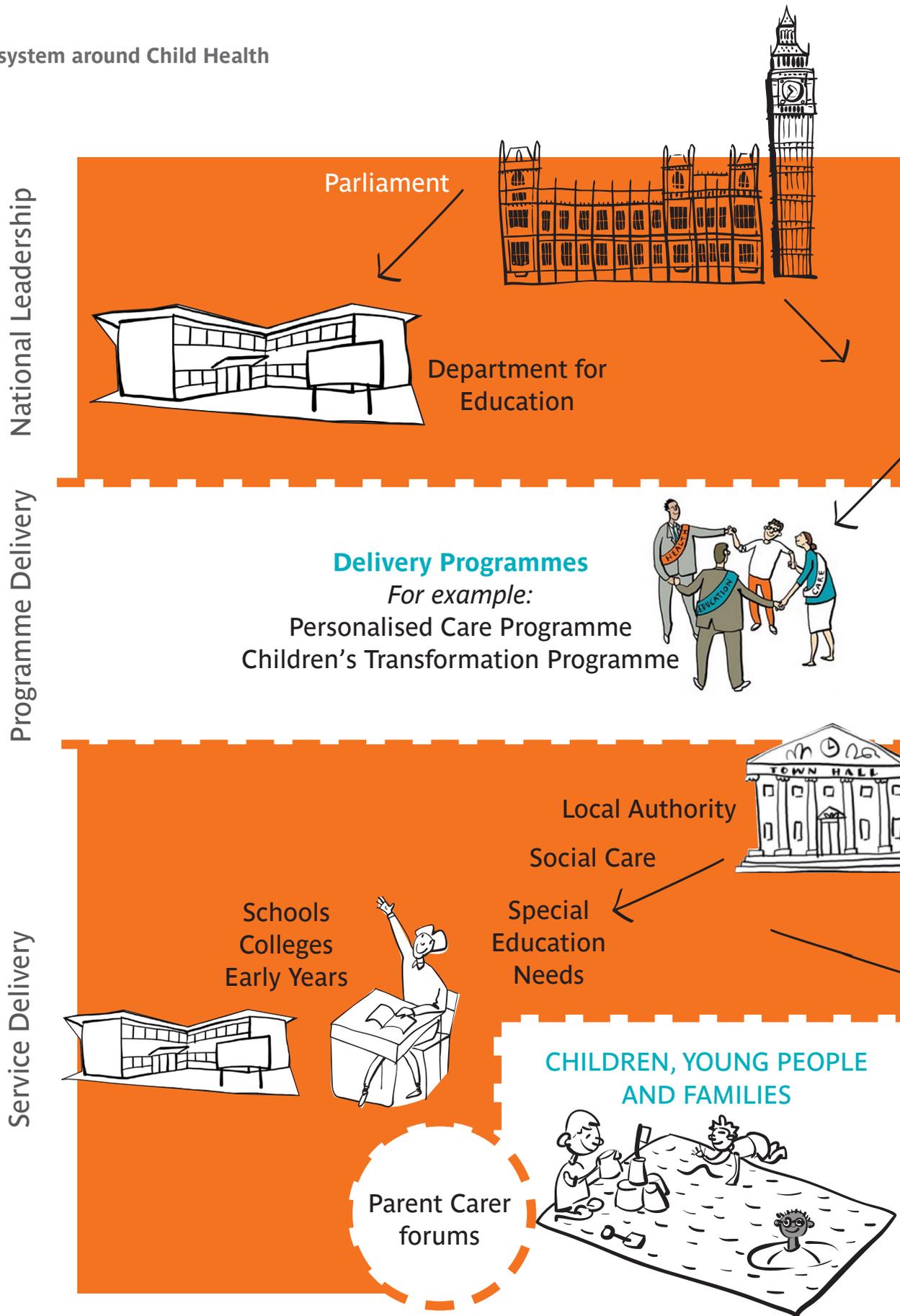


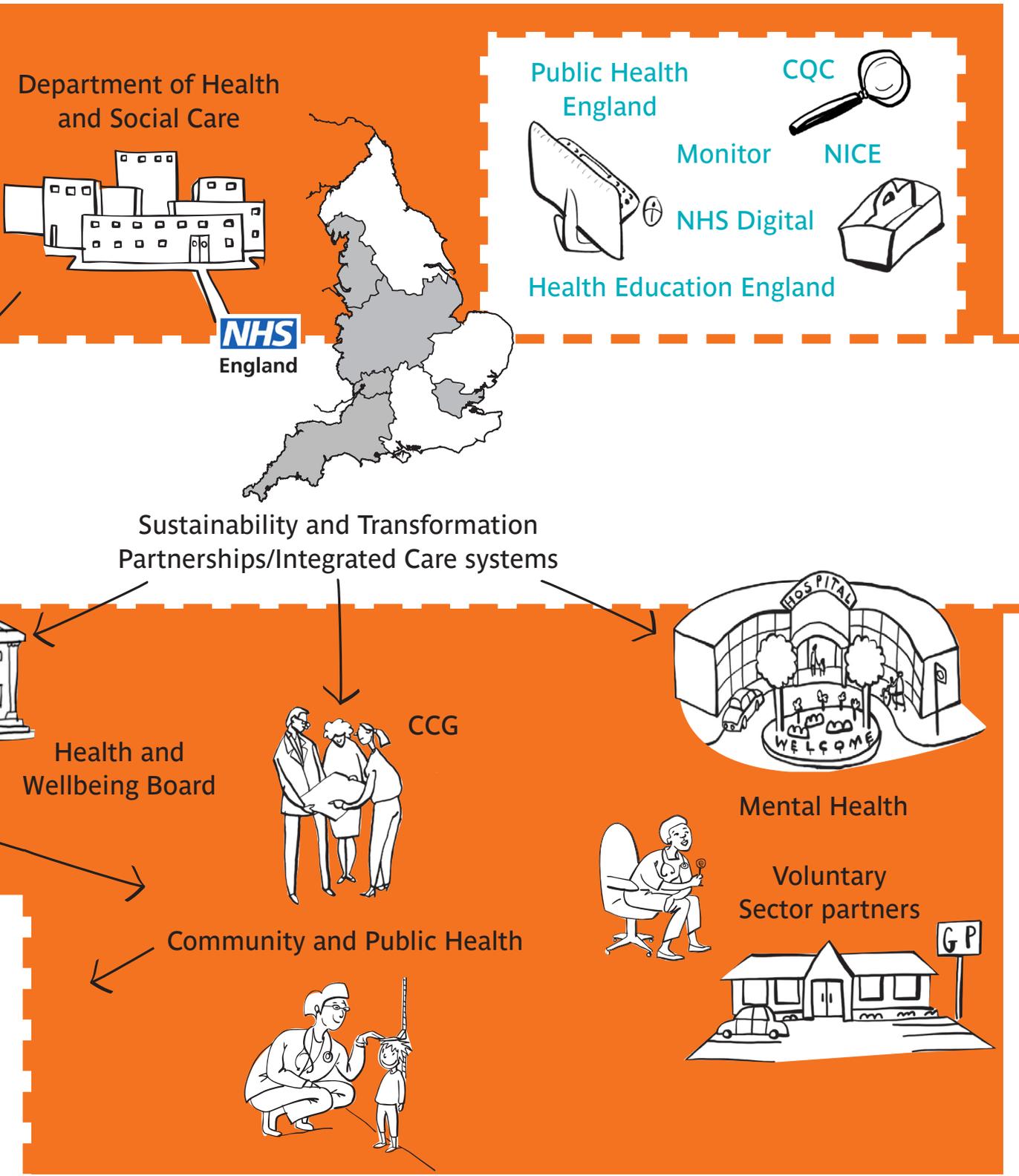
Context: policy and practice

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 are likely, not only to 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.

Figure 1. The system around Child Health





Methods

Further details of our methodology are included in the appendix of the full report.

Our conclusions are 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.

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

In total, we engaged with 74 professionals representative of a range of roles across health, social care and special educational needs services, and included parent carer representatives. Data was analysed using NVivo Framework Analysis software.

Our findings in these three local areas are supported by evidence from our work with local areas across the country and by our analysis of the Ofsted and CQC inspection reports into the progress of implementation of the Children and Families Act 2014 reforms.



Findings of the report

Government policy – a lever and an obstacle

Local areas had been impacted by a number of change programmes from the Department for Education and NHS England. 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.

“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

However in some cases national directives were seen as unhelpful, where:

- pressure to implement change within tight timescales and against a backdrop of stretched resources risked compromising quality;
- the lack of join up between government departments and NHS England in developing and implementing change programmes, hampered interagency working;
- national operational targets and reporting requirements placed on different agencies and services did not align.

In addition participants felt that the outcomes universal services, especially schools, were working towards and assessed on did not always

enable them to effectively include disabled children and young people. This is supported by data on exclusions from mainstream schools: 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

Increasing demand was a key concern in all areas. Recent analysis commissioned by CDC and the True Colours Trust has shown that the numbers of children and young people with complex needs or life-limiting conditions in schools has increased by over 50% between 2004 and 2017. (Pinney, 2017).

Resource constraints were a consistent theme in discussions with participants.

“...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

The figures on this are stark: local authorities have seen a 49% real-terms reduction in government funding between 2010-2018 (National Audit Office, 2018), whilst CCGs began 2018/19 with an estimated underlying deficit of £400-500m (King's Fund, 2018).

Whilst participants acknowledged that initially austerity had generated creativity and supported a shift towards integrated working, as the cuts continued, many felt that the requirement to carry out further restructures had undermined these benefits.

A number of participants explained that joint working and joint commissioning had in fact become more difficult as each partner organisation turned their focus to managing financial pressures. In two cases existing 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

Allocation of funding within health, where the funding for children’s services is often tied up in block contracts and all-age service spending, was also a particular challenge, as commissioners struggled to direct and even distinguish spending on children. 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.

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.

In those areas where they felt supported by senior leadership, participants:

- had a more positive impression of local area strategies and how these related to and could frame their own work;
- were more confident of receiving support when escalating issues and concerns. ***“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***



Conversely, 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.

“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.... 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

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.

However, this dependence on informal relationships was recognised as a less sustainable approach to integration as it could falter with personnel changes. It also seemed to lead to significant inefficiencies with managers spending time agreeing individual packages of care because an area wide approach had not been agreed.

Data and information-sharing

Good quality data and effective information sharing processes should aid integration at both strategic and individual care level,

supporting areas to look at the ‘big picture’, respond together as a system and achieve strategic outcomes. However areas are held back both by practical challenges and by the traditional focus on specific services and cohorts. Leadership has a role to play in promoting work to overcome these barriers.

Population data was generally perceived as poor and patchy and of limited usefulness by participants. This is not only a local but a national issue (Pinney, 2017).

Even where participants did have access to good quality population data this did not necessarily result in needs based commissioning as it tended to inform a service or agency rather than a local area approach.

“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

Measuring progress against narrow, service-specific targets was common practice but felt, by all professionals, to be insufficient in illustrating the impact public services were having on families’ lives. All areas were attempting to develop more effective methods of measuring impact in a meaningful way. However even where local areas had defined a clear set of outcomes tracking their success in achieving them was a significant challenge.

“...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 B

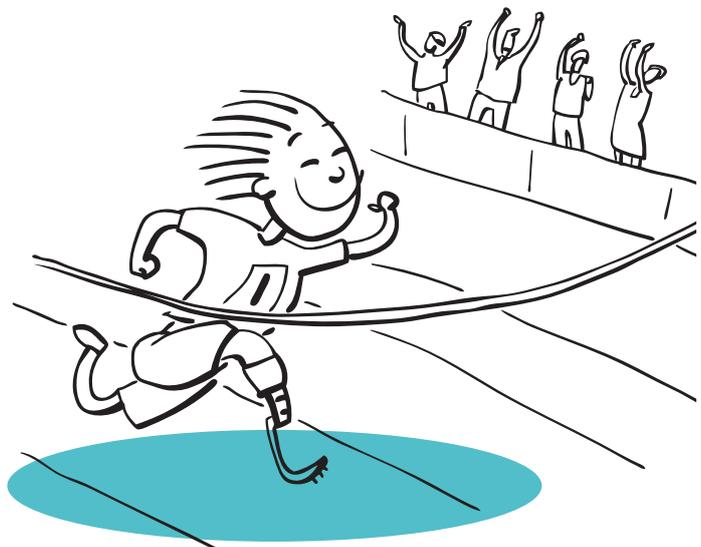
Participants were clear that the lack of a joined up government approach to integration around data added to the challenge of measuring progress and outcomes in a meaningful way.

Individual-level data and information sharing processes, which enable different organisations to share information relating to individual children and young people, were seen as 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.

Where information sharing processes had been established arrangements were not always successful once in place. In some cases this appeared to be due to a failure to involve all relevant colleagues in the development of the new system or process, leading to low levels of commitment to maintaining shared datasets.

A lack of formal processes 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



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.

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 role (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 where 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** 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, where 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 the differing referral processes, threshold criteria, delivery models and funding mechanisms which apply to different agencies and services 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.
- **At individual level**, building dedicated time and space into support planning processes for a **person-centred conversation** with the child or young person and their family, and ensuring this conversation informs the rest of the process and any resulting support package, can support integration through uniting 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.

INVOLVING 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.
- 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 Health and Social Care (Safety and Quality) Act 2015 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 review local government funding for services for children and young people with SEND as rapidly as possible in response to the concerns raised both in this report and wider publications and media reports.

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

NHS England should, having set goals for children's health services, ensure that they hold CCGs to account on progress towards those goals, ensuring that 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 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 cover 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.

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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