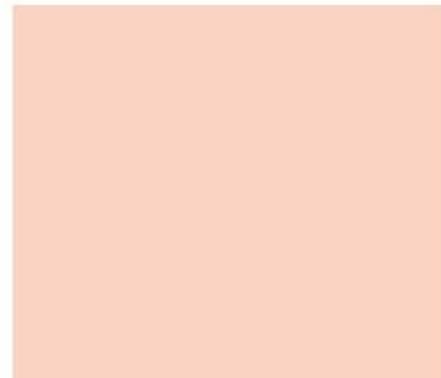
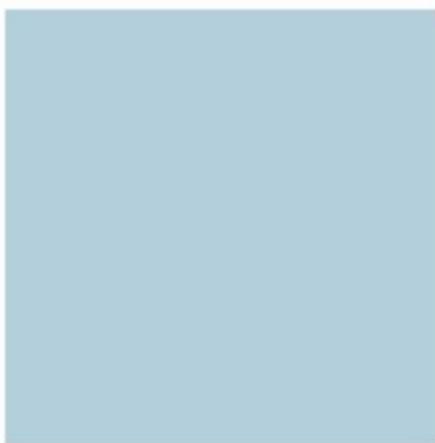


**A new offer:
Information, Advice and Guidance/Support for
Families under a reformed SEND system**



What is the problem?

“Too many families find themselves in a battle with a system that’s supposed to help them. Our reforms will fundamentally transform the system so that children and young people with SEN receive a joined up approach that meets their needs.”

(Edward Timpson, Parliamentary Undersecretary of State, Department for Education)

Under the pre-existing system families have found it difficult to:

- Find accurate up-to-date information in one place about what is available to them in their locality
- Know about options
- Know what is available ‘free,’ what they may be expected to pay for and accurate costs
- Understand how the various organisations and professionals are working together
- Know where to go for advice and support
- Find personal support from someone who knows the system to help them interpret information and guide them in the right direction.

This means it can be difficult or impossible for a family to make plans for the future. The system can appear to lack coherence making planning stressful and inefficient. It can, in the worse cases lead to crisis or family breakdown.

Commissioning the right information, advice and guidance/support (IAG/S) is challenging. We know, for example there can be variable coverage across different parts of a local authority/CCG(s). We know too that there can be ‘too much information’ from multiple sources, and that this can be contradictory or confusing. This applies whether families need general advice about say universal play services, welfare benefits or access to child health services; or more specialist support as a result of a particular condition or syndrome. Sometimes IAG/S is available in one format but not in another, for example, on-line perhaps but not in paper form; in some local authorities key workers/ing is available to provide support and signposting but not in others.

The Children and Families Bill and the SEND reforms

Many of the challenges of providing IAG/S are being addressed by the reforms, for example:

- *Co-production*, that is to say the involvement of parents and young people as partners in the process
- A new duty on local authorities to maintain a local offer which *should provide information for parents and young people about where to get advice, information and support*
- New joined up assessments & Education, Health & Care Plans
- A new *joint commissioning* duty
- *Key working, advocacy and independent parental supporters*¹.

The local offer & commissioning IAG

Local areas are already devoting significant time to work on the development of a local offer which will meet the new statutory requirement to provide web-based as well as paper-based sources of information about what is available in the local area for children and young people with SEND. In some areas we are seeing local authorities work with their neighbouring authorities to ensure coherence and consistency. See for example the SE7 Pathfinder's principles for their local offer.²

The joint arrangements that local authorities and CCGs must have for commissioning education, health and care provision for children and young people with SEND must include arrangements for considering and agreeing what information and advice is to be provided, by whom and how it is to be provided. The local offer must also include details of how this impartial information, advice and support can be accessed and how it is resourced.

¹ In January DfE announced a new £30 million fund for more than 1,900 independent supporters to help parents navigate the new SEN process.

See: http://www.ncb.org.uk/media/1102886/independent_support_q_and_a.pdf
See also Appendix 2 below.

² <http://se7pathfinder.files.wordpress.com/2013/10/se7localofferframeworkfinal.pdf>

The key underpinning competencies of an excellent information and advice service include the capacity to capture, store and retrieve information quickly and efficiently in order to meet *individual* demands and circumstances. Modern information technology solutions make this increasingly achievable.

The draft SEN COP states that local authorities:

“... must take steps to ensure that parents and/or young people are actively supported in contributing to assessments, planning and reviewing EHC plans and that families and young people should have access to impartial advice, information and support to enable them to exercise their rights.”

“... that this should be in the form of a ‘family centred service’; should cover SEN, health and social care; should be confidential and free and should be provided at arm’s length from commissioners in the council and the NHS clinical commissioning group.”

“... that advice and information services should have the capacity to handle initial phone, electronic, or face-to-face enquiries, and preferably be located in easily accessible premises that are independent of the local authority and CCGs.”

The draft Code acknowledges that because the type of support needed for children and young people as opposed to parents/carers may differ significantly, local authorities should consider providing a *separate service* for young people. If they do, then the single point of access for information, advice and support should refer young people to this service, and should work closely with it, in order to ensure co-ordination and continuity across services from 0 to 25.

Universal services & User-led organisations

It is important to remember however that often children and young people with SEND and their families’ overriding need is to know about what they can expect from mainstream or universal services including schools, colleges and their local health services. In areas such as Gloucestershire and Newcastle we are seeing strong direction and leadership from their Health and Wellbeing Boards to the personalising of universal services. Commissioners have a key role to play in building the capacity

of universal services. See *Making It Personal How to Commission for Personalisation Guidance for commissioners and others in children's services*.³

This needs balanced against the major lessons-learned from the experience of adult social care services, where the contribution of 'user-led organisations,' often designated centres for independent living providing peer support at important moments in an individual or family journey, has made the critical difference for people responding to what feels like a crisis.

Information, advice and support services should have clear terms of reference and a development plan setting out needs and priorities for the service. They should review and publish information annually about the effectiveness of the service, including customer satisfaction.

Responsibility for ensuring that this happens rests squarely with the commissioners who, working with parents and young people as partners, need to ensure that there is a 'single point of access' to information and advice about the local system for children and young people with SEND 0-25.

See Appendix 1 for further detail about IAG/S provided in the draft COP.

Mapping

There are already a significant number of organisations and people within the system who provide IAG/S – including parents/carers and young people.

We believe that the SEND reforms provide a unique opportunity to map, review and potentially reshape and re-commission key working and other IAG/S support in local areas preferably in conjunction with adult services.

Each local area is different and we have no expectations of capturing the full range of IAG/S activity in this short paper, even in outline.

We began a conversation with In Control members at the residential event in November 2013 when we asked colleagues: '*Where do families get information, advice and guidance today?*' The results below give an idea of the range of IAG/S which can be found in most local areas across the country:

³ <http://www.kids.org.uk/mip2>

- GPs
- Schools
- Colleges
- Early Intervention workers
- Early Years Team
- Health Visitors
- Children's centres
- Village agents (Gloucestershire)
- Connexions
- Local Healthwatch – see Appendix 2
- Local authority contact centres
- ACE Education Advice & Training (ACE successors)
- IPSE (Institute for Policy Studies in Education)
- Disability-specific services which families use
- Parent Partnerships – see appendix 2
- Centres for Independent Living and other user-led organisations
- Carers' centres and carers' partnership
- Learning Disabilities Partnership Boards
- Physical Inclusion Network
- On-line special needs network (Northeast)
- Disability service hubs (Hertfordshire)
- Multidisciplinary teams
- Disabled children's teams
- Educational psychologists
- Care co-ordinators
- Transition teams
- Brokerage service
- Newsletters/magazines commissioned by councils
- e-newsletter, linked to register for disabled children and young people
- Parent Forum newsletter⁴
- Partners in Policymaking network (for graduates of this programme)
- CAB
- Family Information Services⁵
- Other information services
- Youth information service
- Google, Facebook, Wikipedia
- Various smartphone apps
- Multiagency safeguarding hub (MASH)
- Other
- Other parents
- Mediators
- Other third sector organisations

^{4 5} See Appendix 2

Making a local list of this sort would be a useful exercise for many commissioners and their partners: the remit, geographical coverage, costs, outcomes of each information provider on the list needs to be made clear as part of the process.

Meeting the challenge of the reforms: ten key principles

The length of this list is suggestive of the overriding challenge for commissioners: how to design a local information, advice and guidance/support infrastructure that is able to signpost a young person and/or parent/carer – whatever their needs or their particular situation – to the help they need with the minimum of fuss and the maximum of efficiency. This is no small task; many people find themselves in complicated situations, facing multiple emotional, physical and often financial challenges and of course each family's situation is different.

What is clear from the above and from the feedback from those working and using services across the country is that we cannot *prescribe* a model or an approach. In designing or re-designing the local system, commissioners *must* take account of local need, local family views and the pre-existing local infrastructure - and these vary significantly.

We offer here a short list of the key principles that might underpin a reformed locality system:

1. **Impartiality:** Information must be available in ways that preserve its neutrality so that young people and families can make decisions for themselves.
2. **Accessibility:** Information must be readily and speedily available, where anyone lives.
3. **Co-production:** Information, advice and guidance services must involve families in their design and management and in providing and responding to on-going feedback.
4. **Geographical specificity:** Information must reflect different communities and different services across a locality.
5. **Multiple formats and languages:** Information must be available to all whatever their communication needs or levels of understanding. It must be both online and off-line.
6. **Cultural sensitivity:** Information must reflect the needs and cultural sensitivities of the whole population.
7. **Speed:** Information must be available quickly and be up-to-date.
8. **Diversity of need:** Information must address the very wide variety of need and circumstances families face.

9. **Signposting:** Information services must be in a position to signpost families on to *specialist* or *generic* information providers whenever appropriate.
10. **Advice, guidance and support:** Neutral information must be complemented by the provision of a service to advise, guide and support families face-to-face when they require this.

Recommendations

- A. Local authorities should review the provision of information, advice and guidance/support for families and young people with special educational needs or disability aged, 0-25:
 - a. In partnership with the appropriate Clinical Commissioning Group(s).
 - b. In partnership with local families, young people and organisations representing them.
 - c. By bench-marking current practice against the ten principles above; make this a simple process, perhaps by facilitating an interactive workshop for key players including families and young people following an initial survey of family views and experiences. A simple traffic light rating system for each of the ten principles will suffice.
- B. Commissioners should always regard information and advice services for disabled children and children with SEN as sitting within a wider complex of information services in their locality. Part of their job is to ensure the competency of those wider services. Health and Wellbeing Boards should discuss and agree their commitment to personalisation and, if necessary, re-commissioning IAG/S.
- C. It is imperative that commissioners acknowledge and take account of the emotional impact of SEN and/or disability and the important contribution of peer-support through user-led organisations in responding to family need.
- D. Commissioners together with the key partners listed in A above should produce a SMART action plan to address identified shortfalls and problems.

- E. Commissioners will now be held to account to deliver improvements. They should agree with stakeholders how on-going quality assurance arrangements will operate and how the community will hold them to account.

Final comments:

We are actively seeking to work with authorities who are considering re-commissioning IAG and might be interested in working with us to develop further learning and good practice in this area.

Please contact Claire Lazarus or Andrew Tyson if you are interested and or have any thoughts/comments on this paper.

claire.lazarus@in-control.org.uk

andrew.tyson@in-control.org.uk

Appendix 1 – additional information about IAS from the draft Code Of Practice

Local authorities should provide information and advice on all matters relating to SEN including:

- Local policy and practice;
- The local offer;
- Personalisation and personal budgets; and
- Education law on SEN and related law on disability, health and social care, through suitably independently trained staff.

The advice and support offered to children, young people and parents should include:

- Where requested by parents or young people seeking an EHC plan, and subject to availability, the offer of an Independent Supporter - a trained, independent individual from the voluntary or private sector, to help them through the statutory process, from requesting an assessment through to the agreement of the EHC plan and any associated personal budget;
- Key working support such as:
 - Individual casework and informal advocacy,
 - Support in attending meetings, contributing to assessments and reviews, and participating in decisions about outcomes for the child or young person;
- Help when things go wrong, including resolving disagreements and providing support to manage mediation, appeals, exclusions, and complaints on matters related to SEN;
- Directing parents, young people and those who support and work with them to additional support services where needed, including services provided by the voluntary sector. These services should include housing support, careers advice and employment support and may include volunteer supporters trained by the information and advice service; working separately and impartially with young people and their parents to resolve any disagreements between them; and contributing to strategic development of services by the local authority/CCG.
- Brokers re spend PBs, management PAs etc.

Appendix 2 providers of IAG/S

Parent Partnerships – local authorities have a current duty to commission a Parent Partnership Service. Designed to be free, impartial and confidential many are provided in-house, others through the third or private sectors. The reforms propose to extend their remit beyond the provision of a menu of flexible services for parents of children who have SEN to include health and social care services as well as support to young people. (Many see this as a major challenge).

The National Network of Parent Partnership Services based at the Council for Disabled Children supports and promotes the work of **Parent Partnership Services** across England. See: <http://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/national-parent-partnership-network>

Parent Participation and Information: The National Network of Parent Carer Forums (NNPCF), promotes parent participation at the local level and facilitates a two-way flow of intelligence and thinking between local practice and national policy making. The promotion of parents' voice is central to the process of improving and monitoring the quality of information, advice and support services in localities. NNPCF works closely with Contact a Family and produce a joint bulletin for parents. See <http://www.nnpcf.org.uk> for more information.

Parent-led Parent Carer Forums operate in all local authority areas now and in some areas are being commissioned to provide IAG – please see examples below. NNPCF's nine regional structures promote and facilitate peer support between local Partnerships.

Contact a Family: Provide access to resources, reports and information about parent/carer participation; expertise in engagement, participation and co-production; and expertise in the development, strengthening and sustaining of parent carer forums. They provide a free national helpline for families of children with SEN as well as a regional advisers to support local areas. See <http://www.cafamily.org.uk> for more information.

Independent Supporters: This January the Department for Education announced £30m to fund more than 1800 trained independent supporters to help parents navigate the new SEN process from September 2014. Central funding will be available until March 2016. The supporters will be drawn from the independent, voluntary and community organisations. The

Council for Disabled Children (CDC) are overseeing the recruitment and training of the supporters - around 12 per area. See

http://www.ncb.org.uk/media/1102886/independent_support_q_and_a.pdf for more information.

Mediation: The offer of mediation meetings for parents of children with SEN and their local education authority or the child's school when there is some kind of disagreement surrounding how best to meet those needs. Mediation is an informal, voluntary process where parties in disagreement meet together with an independent mediator. Many local authorities commission this offer from a regional service e.g. the charity Kids provides mediation services for the London boroughs. See <http://www.kids.org.uk/Event/sen-mediation-service> for more information.

Family Information Services: Provide a range of information on all services available to parents up to the age of 25 if a young person has a disability. FIS also hold up-to-date details of local childcare and early years provision in each area. Usually located within the local authority they have close links with children's centres, Jobcentre Plus, schools, careers advisers, youth clubs and libraries. The Family and Childcare Trust provide support through campaigning, research and through the promotion of local Family Information Services. See <http://www.daycaretrust.org.uk/pages/about-fis.html> for more information.

Healthwatch: The national consumer champion in health and care. They have statutory powers to ensure that the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. Local Healthwatch signposts people to local health and social care services. They also collect and analyse the experiences that people have of local care to help shape local services and feed views and any recommendations to Healthwatch England to act on at a national level. See <http://www.healthwatch.co.uk> for more information.

Voluntary and Community services: IAG support ranges from support provided by national organisations representing particular disability groups such as the National Deaf Children's Society who provide national and local support, to small local voluntary organisations working in one area of the country only.

SENDirect: A new project being developed by the SEND Consortium. It aims to support parents to access information and support about the services they want and need; to provide online tools and information to enable them to manage personal budgets or direct payments; to provide support across sector's to develop products to meet identified needs and therefore create a sustainable marketplace of provision and improve the efficiency of commissioning by providing needs led data to inform their decisions. See <http://sen-direct.org.uk> for more [information](#).

Appendix 3 Exemplars from across the country

In some parts of the country, commissioners have *begun* to work with families and other stakeholders to address the challenge.

We offer below a number of exemplars from our member authorities that are of particular interest because of the centrality of parents/carers in the development of new ways of working and arrangements for IAG.

Oxfordshire Independent Parental Supporters: Volunteers who support parents when dealing with schools or the local authority. 'We aim to provide an Independent Parental Supporter (IPS) for all parents of children with special educational needs (SEN) who ask for one, whatever stage of the code of practice the child is on and whatever the SEN.'

Bury Parents' Forum: Established in 2011 (and incorporated in 2012) supports parents of children with additional needs/ disabilities living in the borough of Bury. Bury Parent's Forum is a registered not for profit local social enterprise company with charitable purposes. All Bury Parent team members have children with social care budgets and have firsthand experience.

Pass it on Newcastle: A network of connected families, workers and agencies, Members commit to passing on information to each other and to the Family Information Service (FIS). They aim to get good relevant information out to families of children with disabilities and special needs and to support families to help each other and stay in the know.