

## **Advice on Data Sharing by Information, Advice and Support Services (July 2017)**

### **Introduction – Summary Advice**

1. I am asked to advise the Information Advice and Support Services Network ('IASSN') on issues relating to the relationship between Information Advice and Support Services ('IASS') and local authorities ('LAs').
  
2. In particular I am asked to advise on the following issues:
  - a. Should IASS agree to receive information from their LA in relation to a group of children and / or young people<sup>1</sup> (for example those about to transfer from a statement to an EHC plan) and then proactively offer support to those children, parent(s) or young people?
  - b. Should IASS accept indirect referrals, for example from schools or professionals, or only accept referrals from children, parents and young people?
  - c. Should IASS staff sit on LA decision making panels?
  
3. I would stress at the outset that I am only able to provide general advice to IASSN and this advice cannot be relied on individual cases or by individual IASS. The issues which are the subject of this advice are heavily fact-sensitive and individual IASS will need to obtain advice on the facts of any particular case. I would of course be happy

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<sup>1</sup> A 'young person' in this context is a person over compulsory school age but under 25; section 83(2) of the Children and Families Act 2014.

to advise any individual IASS or the IASSN further on these issues if the need arises.

4. In summary my advice is as follows:

- a. In my view there is a clear distinction between a situation where children, parents and / or young people have agreed that the LA should refer their cases to the IASS and a situation where the LA refers the case without prior consent. In the former situation it seems to me that it will be permissible for the IASS to contact the children, parents and / or young people to provide information or advice. However in the latter situation there is a real risk that the LA would be acting unlawfully by sharing this information and the IASS would be acting unlawfully by 'processing' it, including storing the information and contacting the data subjects. Where a young person or parent lacks capacity to decide whether to access information or advice it may be that an LA can properly refer the case to the IASS on a best interests basis.
- b. Again I would draw a clear distinction between a situation where a child, parent or young person has requested or agreed to a referral by a school or professional to the IASS and a situation where the professional makes the referral at their own initiative and without obtaining consent. In the former situation it seems to me that the IASS can respond to the referral by providing the child, parent or young person with information or advice. However in the latter situation the referring school or professional may have acted unlawfully by sharing this information and the IASS may act unlawfully by 'processing' it, i.e. storing or using it.
- c. IASS staff should not sit on LA decision making panels as this runs directly contrary to the fundamental principle that IASS should be impartial.

5. My detailed advice below draws on an advice produced on 29 April 2016 ('the previous advice') which set out in the relevant law in some detail. To avoid repetition I cross-refer to the relevant sections of the previous advice below.

## **BACKGROUND**

6. The IASSN supports and promotes the work of IASS across England. Under the Children and Families Act 2014, IASS have replaced former Parent Partnership Services as statutory providers of free, impartial and confidential information, advice and support on a range of matters concerning disabled children and young people and children and young people with special educational needs.

7. Section 32 of the 2014 Act provides:

### **32. Advice and information**

- (1) A local authority in England must arrange for children and young people for whom it is responsible, and the parents of children for whom it is responsible, to be provided with advice and information about matters relating to the special educational needs of the children or young people concerned.
- (2) A local authority in England must arrange for children and young people in its area with a disability, and the parents of children in its area with a disability, to be provided with

advice and information about matters relating to the disabilities of the children or young people concerned.

- (3) The authority must take such steps as it thinks appropriate for making the services provided under subsections (1) and (2) known to –
  - (a) the parents of children in its area;
  - (b) children in its area;
  - (c) young people in its area;
  - (d) the head teachers, proprietors and principals of schools and post-16 institutions in its area.
  
- (4) The authority may also take such steps as it thinks appropriate for making the services provided under subsections (1) and (2) known to such other persons as it thinks appropriate.”

8. In essence, English local authorities are obliged to secure the provision of advice and information to children for whom they are responsible or who are in their area, and their parents, about matters concerning the special educational needs and disabilities of the children concerned, as well as to take appropriate steps to make such services known to specified persons, including the parents and the children themselves (as well as head teachers and such other persons as the local authority thinks appropriate).

9. Section 32 of the Act thus contains the key duty pursuant to which IASS are provided ('the section 32 duty'). I understand that while most IASS are provided by local authorities around 25% are provided by voluntary sector organisations. The duty is for local authorities to 'arrange' for IASS to be provided, and not to provide IASS themselves. Essentially, local authorities have an obligation to secure

the provision of IASS, but it is left to the judgment of each local authority as to precisely how, and by whom, the services will actually be provided.

10. The Code of Practice ('CoP') for SEN and disability was introduced pursuant to section 77(1) of the 2014 Act. Section 77(4) provides that a range of persons and bodies including local authorities 'must' have regard to the CoP when exercising their functions under Part 3 of the Act.
11. Chapter 2 of the CoP is entitled 'Impartial information, advice and support', and concerns the information, advice and support ("IAS") which local authorities 'must' provide for 'children, young people and parents' covering special educational needs, disability, health and social care.
12. Paragraph 2.4 of the CoP notes that IAS should be provided through a 'dedicated and easily identifiable service'. It refers to the fact that local authorities have 'established Parent Partnership Services to provide information, advice and support to parents in relation to SEN', and that many local authorities provide or commission IASS 'for young people'. Paragraph 2.4 goes on to say that local authorities should 'build on' these existing services, to provide the IAS detailed in Chapter 2 of the CoP. Such services should be impartial, confidential and accessible, and should have the capacity to handle face-to-face, telephone and electronic enquiries (CoP, para. 2.5).
13. Para 2.8 states that (emphasis added):
  - a. 'The information, advice and support should be impartial and provided at arm's length from the local authority and CCGs

- b. 'The information, advice and support offered should be free, accurate, confidential and in formats which are accessible and responsive to the needs of users.'
  - c. 'The provision of information, advice and support should help to promote independence and self-advocacy for children, young people and parents.'
14. Para 2.15 states 'Young people **must** have confidence that they are receiving confidential and impartial information, advice and support.'
15. Chapter 2 of the CoP goes on to consider a number of other matters, such as the precise scope of the IAS which local authorities are required to provide. The CoP does not define how children, parents or young people should be referred to IASS.

## **ADVICE**

### A. Receiving information from LAs and proactively contacting families

16. The key duty on LAs under section 32 is to arrange for children, parents and young people 'to be provided with advice and information'. There is nothing in the legislation that states that the request for advice and information must come directly from the child, parent or young person. It is very likely that in many cases a direct request will be made, and LAs have the duty to take appropriate steps to ensure that children, young people and parents are aware of the IASS in order to facilitate such requests. LAs must also take appropriate steps to ensure that 'head teachers, proprietors and principals of schools and post-16 institutions' are aware of the IASS, and may take such steps as they think appropriate to make others aware of it.

17. In this context it seems to me that there is nothing objectionable about LAs asking children, parents and young people if they want their details to be passed to the IASS who will then contact them to offer them impartial advice and support. So long as the child is competent or the parent or young person has capacity<sup>2</sup> to make this decision then their informed consent would seem to me to make it lawful for the LA to provide their contact details to the IASS and the IASS to make contact with them. In this situation there does not appear to be any breach of confidence or of the Data Protection Act 1998 ('DPA').

18. Different considerations arise where a parent or young person is assessed to lack capacity (for the purposes of the Mental Capacity Act 2005, 'MCA') to decide whether to access information or advice.<sup>3</sup> In my view these cases are likely to be rare, as a decision to seek information or advice is a relatively 'low level' decision. However if a proper capacity assessment is negative on this point, applying the criteria in sections 2 and 3 of the MCA, then the LA is likely to be able to make a decision as to whether information or advice should be provided in the person's best interests. Of course it will be important that the IASS accepts and agrees with this best interests decision.

19. However in my view the position is very different if LAs take it upon themselves to provide information in relation to children, parents and young people to IASS without their consent where there

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<sup>2</sup> The approach to assessment of children's competence and parents and young people's capacity to make decisions is set out in my advice with my colleague Michael Armitage dated 3 February 2015 at paras 36-53. The definitions of 'lacking capacity' and 'unable to make a decision for himself' are found in sections 2 and 3 MCA.

<sup>3</sup> A child may well not be competent to make this decision, however in the vast majority of such cases it will then fall to the parent to decide whether to request information or advice as this issue will be within the 'zone of parental control', see para 52 of my advice with Michael Armitage dated 3 February 2015. For young people who lack capacity, then a complex set of statutory provisions require that information and advice should also be provided to their 'representatives', who would be a Deputy or person with Lasting Power of Attorney or (in the absence of either of the above) their parent.

is no evidence of incapacity<sup>4</sup> to make the decision to access information or advice. It is perfectly possible in my view that children, parents or young people would not welcome an unsolicited offer of information or advice from an IASS – for example if they were dissatisfied with a previous experience of support from an IASS or if they had developed significant expertise of their own in relation to the SEN system or local provision. It is also inconsistent with the requirement in the CoP at para 2.8 that ‘information, advice and support should be impartial and provided at arm’s length from the local authority’.

20. Firstly, it is likely that (for the reasons given at paras 16-24 of my previous advice) information held by LAs in relation to children or young people with special educational needs and / or disabilities will be confidential. Sharing this information without consent or the existence of a pressing need to do so is likely to result in a breach of confidence, including where the information is shared with an in-house service. It may also amount to misuse of private information (see paras 25-26 of my previous advice) and / or a breach of Article 8 ECHR (para 27 of my previous advice).

21. Although the primary responsibility for any legal breach may rest with the LA for sharing this information, the IASS may potentially acquire liability by accepting and storing it, or in particular by using it for any purpose.<sup>5</sup> Further advice would need to be given on this relatively complex issue on the facts of a particular case.

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<sup>4</sup> One of the fundamental principles of the MCA is that capacity is to be presumed in the absence of evidence to the contrary, see section 1(2). This applies to all those over 16, including young people.

<sup>5</sup> Of course in most cases the IASS is part of the LA and does not have a distinct legal personality, but even the minority of IASS which are run by separate organisations may share a degree of responsibility for legal breaches if information is received, stored and/or used in any way.

22. Significant issues also arise under the Data Protection Act 1998 ('DPA'), see paras 28-46 of my previous advice. Information shared by the LA with an IASS may constitute 'sensitive personal data' for DPA purposes.<sup>6</sup> Sensitive personal data should not be shared without explicit consent other than in exceptional circumstances such as safeguarding concerns. Even if the information shared by the LA is only 'personal data', then consent<sup>7</sup> is arguably the safest way to ensure that there is no breach of the DPA.<sup>8</sup> Consent should be informed, in other words the child, parent or young person must be clear about what information may be shared, with whom and for what purpose. A 'tick box' approach will not be sufficient if the data subject does not have the necessary information to give informed consent.

23. Furthermore I would highlight the second data protection principle under the DPA, being that 'personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes'. As such if a LA obtains personal data on a child, parent or young person for the purposes of completing an EHC needs assessment, it may breach the second data protection principle for

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<sup>6</sup> Under section 2 DPA, 'sensitive personal data' includes 'personal data consisting of information as to... physical or mental health or condition'. Even if the information shared by an LA with an IASS is limited to contact details, it is being provided on the basis that the child or young person has a disability and / or a special educational need. It may be said that identifying information which clearly indicates that a child or young person has a special educational need and / or disability is information 'as to' their physical or mental health or condition.

<sup>7</sup> The ICO guide states, 'Consent is not defined in the Data Protection Act. However, the European Data Protection Directive (to which the Act gives effect) defines an individual's consent as: "...any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed."'

<sup>8</sup> An LA may argue that processing personal data in this context is necessary to exercise its function under the CFA 2014 of arranging the provision of advice and information, or indeed that another of the relevant conditions in schedule 2 DPA is met. However it seems to me that such an argument would be unlikely to succeed where it would have been possible to obtain consent to process the data for this purpose and there is in any event no specific duty to provide information or advice to individual children, parents or young people. Furthermore the ICO highlights that the requirement of necessity in the schedule 2 conditions will not be met 'if the organisation can achieve the purpose by some other reasonable means or if the processing is necessary only because the organisation has decided to operate its business in a particular way.'

that data to be transferred to the IASS for the purpose of offering information and advice – albeit that there is no obvious incompatibility between these two purposes.

24. It seems to me unlikely that a LA would be able to rely on implied consent for contact to be made by an IASS where data was provided for a specific purpose, for example obtaining an EHC needs assessment. This would seem to me be potentially unfair processing of the data, which would contravene the overarching requirement of the DPA. It may be easier to rely on implied consent to provide the data to the IASS where the data was obtained following a broader request for assistance from the LA. Conversely it will be harder still to rely on implied consent where there has been no recent approach for support, for example where children are awaiting transfer from statements of SEN to EHC plans. Of course this issue can be avoided entirely if explicit consent for the information to be given to the IASS is obtained by the LA at the relevant time.
25. It is important to note that the restrictions in the DPA apply to 'processing' of data, which has a very wide definition.<sup>9</sup> As such even if the IASS is an 'in house' service there may well be a breach of the DPA if data is 'processed' by the LA providing it to the IASS and by the IASS storing it and / or using it to make contact with the child, parent or young person.
26. I would also highlight that the data sharing code of practice produced by the Information Commissioners Office states that 'The general rule in the DPA is that individuals should, at least, be aware that personal data about them has been, or is going to be, shared –

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<sup>9</sup> Under section 1 DPA, 'processing' means 'obtaining, recording or holding the information or data or carrying out any operation or set of operations on the information or data'.

even if their consent for the sharing is not needed'. Under this code of practice, data sharing expressly includes 'the sharing of data between different parts of an organisation' and so again this principle applies to in house IASS as well as those provided by the voluntary sector. As set out in para 43 of my previous advice, if data is to be routinely shared between the LA and an IASS then a data sharing agreement should be in place which may involve carrying out a privacy impact assessment.

27. For all the above reasons therefore my view is that IASS should only accept information in relation to children, parents or young people from the LA and use this information to make contact to offer support if it is clear that:

- a. There is informed consent (see para 22 above) to this information being provided and used in this way; or
- b. The relevant individuals lack capacity in this regard and a proper best interests decision has been taken that the IASS should offer them information or advice; or
- c. The IASS is satisfied that the information is otherwise being provided lawfully, for example that relevant condition(s) in the DPA schedules are met and there is no breach of confidence. I would suggest that case specific advice would be needed before such a decision was made.

28. I would strongly advise that any IASS which is asked to receive information from the LA and make contact with children, parents or young people where there is no evidence of informed consent to do so should obtain specific advice on the facts of that case before agreeing to any such request.

29. Finally, external IASS provided by voluntary sector organisations will need to check their contract with the LA to ensure

that it does not oblige them to accept in any way different to that set out above. If there are any concerns about the contract then specific advice should be sought.<sup>10</sup>

## B. Indirect referrals

30. My advice in relation to indirect referrals is similar to that in relation to referrals from LAs as set out above. In essence, it seems to me that IASS should only accept and act on indirect referrals from professionals or others where there is clear evidence of informed consent to this referral by the child, parent or young person. In my view accepting an indirect referral made without informed consent and making contact with the child, parent or young person is likely to be unlawful for all the reasons set out above. However I can see nothing objectionable to an IASS receiving and acting on a referral from a professional or other concerned individual where this is made with the informed consent of the child, parent or young person.
31. The same caveat would apply here in relation to the (probably rare) cases where a parent or young person is assessed as lacking capacity to decide whether to access information or advice. In such cases it may be that a best interests decision could be made to refer the person to the IASS so that appropriately tailored information or advice could be offered.
32. In other situations the IASS would need to be satisfied that the information was being provided lawfully, for which case specific advice would be required.

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<sup>10</sup> One of the conditions in schedule 2 DPA which allows the processing of personal data is that 'The processing is necessary for the performance of a contract to which the data subject is a party'. However the data subject (i.e. the child, parent or young person) will not be a party to the contract between the LA and an external IASS, so this condition will not apply.

### C. Decision making panels

33. I am firmly of the view that it is inappropriate for IASS staff to sit on LA decision making panels. The CoP emphasises that IASS must be 'arms length' and 'impartial'. It seems to me to be impossible for an IASS to be 'arms length' or 'impartial' if its staff are taking an active part in LA decision making, for example as to whether to carry out an EHC needs assessment for the child or which placement should be named in a young person's EHC plan. Equally for IASS staff to attend decision making panels in any other capacity that accompanying a child, parent or young person would seem to me to run contrary to the requirement of impartiality from the LA unless there is a good reason for this, for example a training need. In such cases the reason for the IASS staff attendance should be clearly explained to the child, parent or young person and it would seem to me to be at least good practice for their agreement to be sought.
34. It is important however to distinguish between IASS staff sitting on decision making panels and acting as supporters or advocates for families at such panel meetings. The latter activity fits plainly within the definition of 'Individual casework and representation' which forms part of the IASS role as explained by para 2.19 of the CoP.
35. I note that the CoP suggests that part of this aspect of the IASS role includes 'support in attending meetings, contributing to assessments and reviews and participating in decisions about outcomes for the child or young person' (emphasis added). The drafting of this section of the CoP is not entirely clear and it could be read as supporting a view that IASS staff can participate in LA decision making processes. However in my view this must be read as

'participating' in the sense of representation for the child, parent or young person. Furthermore on a strict reading this section of the CoP is only suggesting that IASS staff can participate in decisions about 'outcomes' for the child or young person, not about issues such as provision or placement. This section of the CoP must be read in the light of the overall policy intention to ensure that IASS are impartial and arms length. As such it does not undermine my conclusion that IASS staff should not participate in decision making panels or other similar meetings otherwise than in an advocacy role for the child, parent or young person.

## **CONCLUSION**

36. In relation to all three issues on which I have advised above, it is important to keep in mind that the context for the provision of information and advice by IASS is likely to be a dispute between a family and the LA. As such it is of fundamental importance that the impartial, arms length and confidential nature of the IASS is preserved and protected. Ensuring that referrals for children, parents and young people where there is no evidence of incapacity are only accepted on the basis of informed consent and refusing to participate in LA decision making processes will further all these key aspects of the IASS role.

37. I hope this advice is helpful in allowing IASSN to provide guidance to its members in this important and sensitive area. If I can provide any further assistance please contact me in chambers.

Dated 19 July 2017

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Monckton Chambers