

The Inquiry into Hyponatraemia-related Deaths

Chairman: Mr John O'Hara QC

Ms Maeve Hully
Chief Executive
Patient and Client Council
1st Floor, Lesley House
25-27 Wellington Place
BELFAST
BT1 6GD

Our Ref:- JOH-0411-13

Date: 4th October 2013

Dear Ms Hully,

As you may be aware, this Inquiry has been investigating the deaths of a number of children in Northern Ireland and the circumstances surrounding and following those deaths. Each of the deaths was caused or contributed to by hyponatraemia. The Inquiry's public hearings are drawing to a close. They will end in week commencing 11 November, a week which will be devoted to hearing evidence about practices and procedures which are **now** in place and which are intended to make the Health Service safer for and more responsive to patients and their families than might previously have been the case.

It is important for me to understand the extent of changes which have taken place in recent years. The events which I am looking into occurred primarily between 1995 and 2003 when governance was far less well-developed than it is now. I have heard some evidence about various issues including failures to communicate with parents during the treatment of the children and after their deaths, failures to heed or respond to parents' concerns, failures in the complaint system and failures in the investigation of what would now be called serious adverse incidents. I have also heard some evidence which might suggest that there was a failure on the part of doctors and managers to face up to and admit errors and failings which had occurred. It is relevant to note that I heard evidence about the involvement of the Western Health and Social Services Council in events between 2000 and 2003.

The formation of your organisation in 2009, as the successor to the four area Health and Social Services Councils, was intended to ensure that patients and others had "a powerful independent voice", as described on your web site. I am interested in the extent to which you have been able to fulfill that task, the difference which you have made and the extent to which you think that the National Health Service is now more alert and responsive to patients' issues. Accordingly, I invite you to express your views in a paper which will be made public on the Inquiry's web site and which may be referred to at the hearings in week commencing 11 November.

Secretary: Bernie Conlon

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If you accept the offer to provide such a paper, you should do so against the background that I have available to me, and will make public at the Inquiry, your helpful first Annual Report on Health and Social Care Complaints 2011/2012 which was published in November 2012. This shows that year-on-year you have supported more and more complaints.

I also have available and will make public a paper published by the Health and Social Care Board following a workshop held on 14 May 2013. That paper is entitled "Report on the Outcomes from the 'Improving the Complaints Process in the HSC' Workshop". A copy of that report is attached to this letter. As you are no doubt aware some concerns were expressed at that meeting on a range of issues including the adequacy and effectiveness of the complaint system, the public awareness of the existence and role of your Council and the level of support received by individuals who had used your services. Within the report these concerns are referred to specifically at page 6, then at pages 10 – 11 and lead on to recommendation 3 at page 12.

It would be helpful if any response which you make to assist the Inquiry focused on complaints involving hospital services, particularly where they involve children. There are other areas of your work such as mental health, social care and GPs which, while important, are not relevant to the work of this Inquiry.

You are welcome to set out your experience and views in whatever way you prefer. It would, however, be valuable if you could touch in your response on the following topics:

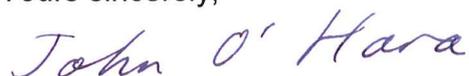
1. How you think that the complaint system in relation to hospital services is now working, especially in relation to the extent to which complainants are involved in the investigation of complaints.
2. How you think the complaint system might be improved.
3. How well you think that medical and nursing staff communicate with children and their parents and listen to them when treating children.
4. Whether you think that investigations of serious adverse incidents have improved in recent years and, if so, how they have improved.
5. How you think that the investigation of serious adverse incidents might be improved upon.
6. How open you think doctors, nurses and managers now are in discussing events which have occurred, accepting criticism and admitting failures.

7. How well you think your Council and its representatives are succeeding in their goal of providing a powerful independent voice.
8. How you suggest your Council's contribution to the Health Service might improve and be developed.
9. The extent, if any, to which you accept the validity of the concerns expressed in the May 2013 workshop about the Council and its work.
10. Any actions which have been taken in response to the concerns expressed at the workshop.

After the public hearings have finished, I have to prepare a report which will go to the Minister and which will then be published. In that report I will set out my conclusions about the events surrounding the treatment and deaths of each child. I then have to make recommendations about improvements or steps which might now be taken to build on progress which there has been in the decade or so which has passed since the children died. Your contribution to that element of my task would be very welcome. If the Council accepts this invitation, I would hope to receive its paper by Friday, 25 October. In the meantime you are free to contact me or the Inquiry solicitor, Ms Anne Dillon, at the address and 'phone number set out at the start of this letter.

Thanking you in anticipation.

Yours sincerely,



John O'Hara

Health and Social Care Board

Report on the Outcomes from the 'Improving the Complaints Process in the HSC' Workshop

Tuesday 14 May 19:00 – 21:00

Introduction

Each year, there are over 4 million interactions within Health and Social Care across Northern Ireland and approximately 6000 complaints are raised by those who have accessed Health and Social Care Services. On 1 April 2009, 'Complaints in Health and Social Care - *Standards and Guidelines for Resolution and Learning*' (the Guidance) was issued for Health and Social Care (HSC) organisations. It was developed in relation to four key principles to include;

- openness and accessibility
- responsiveness
- fairness and independence; and
- learning and improvement

The Guidance also placed greater emphasis upon resolving complaints close to the point of contact, at a Health and Social Care Trust or Family Practitioner Service Level and allowing complainants to have direct recourse to the NI Commissioner for Complaints if local resolution is unsuccessful. All Health and Social Care Organisations have appropriate mechanisms in place to enable patients or clients to raise complaints regarding services which they have received, which they have been unhappy with and/or have been denied. This provides an opportunity for the complainant and the organisation complained against to attempt a prompt and fair resolution of the complaint.

In June 2010 the Department of Health, Social Services and Public Safety (DHSSPS) issued the Health and Social Care Board (the Board) with Terms of Reference to undertake a 'Process Evaluation' of the Guidance. The Board was asked to establish if the new complaints handling arrangements have been fully implemented and identify any

strengths and/or weaknesses of the new arrangements. This Evaluation highlighted 14 recommendations to further enhance the effectiveness of the Guidance, (Appendix 1). Recommendation 11, highlights the importance of establishing a regional mechanism to receive user satisfaction feedback, to ensure that the complaints process is continually improved and enhanced.

To fulfil this objective, the Board, held a regional service user workshop on the 14 May 2013, in Board Headquarters. The aims of the workshop included a review on;

- What works well within the complaints process, what improvements are required and what are the perceived barriers to making a complaint; and
- How a regional mechanism to receive user satisfaction feedback should be created and how it can be implemented.

It was advised that the workshop was not an opportunity to raise a complaint or re-open closed complaints. The Board enlisted the assistance of the Health and Social Care Leadership Centre, to provide an independent element to the process in facilitating, providing feedback and collating information.

Significant efforts were made to promote this workshop to include; a press release in the local papers; advertisements in the regional papers; an interview with the Health and Social Care Board Complaints Manger on 'On your Behalf'; an advertisement in the 'Belfast City Matters' Magazine; a request to General Practitioners to promote the workshop within their Practices; advertisements on Health and Social Care Organisations websites, i.e. the Board, Health and Social Care Trusts and the Patient and Client Council.

Response levels from service users were relatively positive, 38 members of the public registered their interest, 27 of which attended on the evening. On average, 21 service users had made a complaint, compared to 6 individuals who did not use the complaints process following negative experiences. Furthermore, those which expressed an interest in attending but were unable to, contributed their comments via written communication, telephone conversations and face to face

meetings. In addition, 23 members of staff attended to include; representation from the Patient and Client Council, the South Eastern Health and Social Care Trust, the Belfast Health and Social Care Trust, the Northern Ireland Ambulance Service, Family Practitioner Services and the Health and Social Care Board.

The following provides a brief summary of the key themes, main discussions and views identified at the workshop. These findings will be shared with those HSC Organisations who were in attendance and with the Department of Health, Social Services and Public Safety for discussion, in regards to implementing the suggested actions to address concerns.

Key Themes

A number of themes were reviewed on the evening to include;

- Accessibility
- Communication
- Support
- Resolution of complaints
- Learning from complaints
- Perceived barriers to complaining
- Improving the complaints process
- The establishment of a regional mechanism to receive service user feedback

Findings

1. Accessibility

The Complaints Guidance indicates that, all service users should have easy access to the HSC Complaints Procedure and that information should be readily available to enable them to complain about any aspect of the service.

However, evidence from the workshop highlighted the majority of service users in attendance, did not know how to make a formal complaint. In addition, they struggled to find out where to access further information. It was particularly evident, that confusion arose when service users were placed into private nursing homes for respite, as to who has accountability for the investigation for the complaint.

Evidence also showed that when a complaint was lodged, the service user/complainant had to push for results or further communication from the complaints teams as to the status of their complaint. In addition, service users/complainants were not kept fully informed of any changes to policies or practices as a result of their complaint. Therefore, not only did the majority of attendees believe that the complaints procedure was inaccessible, they also did not see the point in making a complaint as there is little/no evidence of learning and/or a change of practice as a result. Service users highlighted that there was a feeling of 'shutters coming down' from the Health and Social Care Organisation being complained against. Furthermore, representatives from 'Patients First,' also highlighted that service users may not know how to complain, or of their right to complain.

2. Communication

The Guidance indicates that, '...local procedures should be easily accessible, open, fair, flexible and conciliatory and should encourage communication on all sides'¹. However, findings from the workshop demonstrated that the level of communication with complainants was poor and that service users were not kept fully informed throughout the

¹ Complaints in Health and Social Care – Standards and Guidelines for Resolution and Learning (Page 5)

process. Attendees highlighted that whilst there was an expectation that somebody would listen to their concerns, this did not occur, therefore they felt that they were not taken seriously and were subsequently 'brushed off'.

It was acknowledged that clear lines of communication, are crucial when providing support to both staff and service users. There was a general consensus that contact between the complainant and the complaint officers was poor and that the onus was on the complainant to seek further information, updates, or explanations as to why delays occurred. In addition, it was felt that there was a lack of timeliness and/or responsiveness from complaints officers and frequently there did not appear to be a dedicated person assigned to follow through individual complaints. Consequently, this led to complainants having to reiterate their story to a variety of complaints officers, which led to increased frustration. It was felt that local resolution did not always work, meaning that the complainant was left feeling increasingly exasperated by the process and the situation escalated as a result. It was acknowledged that communication takes place with carers and next of kin, but there also needs to be consideration of the wider family circle.

Service users expressed disappointment in the administrative process of the complaints procedure as a variety of errors occurred to include; complainants not having the opportunity to review minutes of meetings, suggest amendments or include further action required; the HSC Organisation produced a report, thus closing the complaint without any further discussion from the complainant and their correspondence was sent to the wrong address.

It was suggested that, when a patient is admitted to a hospital/residential facility or becomes registered with a General Practitioner, that they are provided with a 'package of information' to include 'how to make a complaint' and their 'right to complain' if they feel that the standard of care is not appropriate. It was highlighted that the complaints literature which is provided to service users, at times can at times be too vague, it was acknowledged that it should not be overly complicated and no longer than an A4 page. However, there was recognition that there is a

requirement for a flexible approach in regards to complaints handling arrangements (i.e. one size does not fit all).

3. Support

Service users felt that there was limited support available from complaints officers, in assisting individuals wishing to make a complaint. It was acknowledged, that a person may be too emotionally or physically exhausted to go through the complaints process alone, thus additional support is vital.

The majority of attendees, indicated that there is a lack of information available in regards to the role and responsibilities of other bodies such as Regulatory and Quality Improvement Authority, the Northern Ireland Commissioner for Complaints (Ombudsman) and in particular the Patient Client Council. In regards to the latter, the majority of service users either did not know that the Patient and Client Council exists or that they have an advocacy role in supporting complainants through the complaints process. Whilst the Patient and Client Council was established in 2009, service users did not know that their role includes providing advice and support in regards to the complaints process, for example, drafting letters for the complainant, arranging meetings, making telephone calls, and/or referral to other advocacy services.

There was an agreement that there is a requirement for additional advocacy services within Northern Ireland or at least clarification of the roles of the bodies which may provide support to complainants. There were also concerns about the independence of the complaints process, for example, members of staff who have been involved in the care of the patient were also the investigating officers. Therefore, there is a requirement for a greater level of transparency within the investigation of complaints.

4. Resolution of Complaints

Service users indicated that they were reluctant to raise formal complaints, as there is little evidence to show that practices and policies have changed as a result. They felt that they were left waiting far too long for the resolution of complaints. There is a perception amongst service users that if a patient has died or is very unwell, that this creates

a barrier to complaining. Individuals also demonstrated that there is limited action or accountability as a result of making a complaint.

It was deemed that in many cases local resolution is a good option, however frequently complaints were often formalised unnecessarily, for example, complainants may want to raise general concerns about the level of care provided, however they were forced to put these concerns into writing whereas they could have been resolved relatively quickly if a meeting was arranged with the manager in charge of their relatives' care.

In regards to the complaints process, attendees felt that the response letters were often signed by individuals who did not seem to know the nature of the complaint or their situation.

5. Learning from Complaints

Service users demonstrated that if the complaints process was used effectively as a mechanism for improvement and learning, it would not only provide positive outcomes for patients, but it would also reduce the risk of recurrence of similar incidents. However, unfortunately, service users felt that they are not informed of the learning gained from making complaints thus 'complaints' still have negative connotations and complainants subsequently feel that they are seen as 'trouble makers'.

6. Perceived barriers to Complaining

Attendees, highlighted various perceived barriers to complaining, however many agreed that defensive attitudes from staff, lead to fear among patients that they (or their relatives) will be mistreated or receive a worse level of service as a result. In some cases service users felt that 'professional arrogance' was a barrier.

Some individuals indicated that the complaints process itself was a barrier, as a significant portion of the population struggle to articulate their concerns in writing, thus it may be off-putting for those with learning, literacy or language difficulties. It was suggested that all Health and Social Care Organisations display and/or supply information in regards to how to make a complaint, in particular for those in which English is not their first language/ the visually impaired and/or those who have learning disabilities.

Individuals felt that the lack of information about who to make the complaint to was problematic and that there continues to be a lack of discretion/confidentiality in regards to making a complaint.

Service users raised concerns in regards to the lack of advocacy services available and those which can be accessed are not promoted particularly at the grassroots level. The role and responsibility of the Patient and Client Council was raised as those who had used their services did not feel that they were always adequately supported and that the complaints support staff did not fully engage with them.

7. Feedback in relation to Improving the Complaints Process/The Way Forward

There were a variety of constructive suggestions in which the complaints process may be enhanced and improved. It is important that complaints officers remain impartial and that they listen to all sides. In particular, it was felt that rather than a lot of written communication, face to face exchanges would be helpful in the earlier stages with a view to early resolution at a local level. There was a strong emphasis, that there is a requirement for an independent element within the complaints process. Many service users were unaware that independent Lay Persons are available and may assist in the resolution of complaints at an early stage. Their role involves listening to both the complainant and the organisation being complained against and preparing a report outlining their findings and what recommendations they believe should be implemented to ensure prompt resolution.

Greater transparency is required within the HSC Complaints Procedure, particularly within Trusts, in regards to the sharing of outcomes from complaints. It was felt that there should be a certain level of continuity in which the complainant liaises with one person as far as possible until the complaint is resolved.

It was acknowledged that the availability of information and additional support available, to service users was limited and there needs to be greater promotion of the complaints procedure and the roles/responsibilities of other bodies such as the Regulatory and Quality Improvement Authority, the Ombudsman, the Patient, Client Council, and similar support groups.

It was suggested that training would also be beneficial so that staff do not act defensively and would be better equipped to deal with complaints at a local level.

8. Regional Mechanism to Receive User Satisfaction Feedback

Service users indicated that a variety of mechanisms should be developed in order to receive feedback, rather than the formal complaints process. These include;

- Complaints forums throughout Northern Ireland for service users to attend on a biannual basis. These workshops should be facilitated by senior HSCB/HSC Trust managers thus demonstrating that they too are interested in listening to the public therefore reinforcing that their views are taken into consideration
- The development of stamped addressed postcards, which are placed within wards for service users to complete as well as the creation of 'comment boards' within wards in which the public can 'post' their views highlighting their experiences of health and social care.
- Greater use of social media and/or email. This may include either a suggestion box on the Health and Social Care Board/Health and Social Care Trust website or social media forum
- Informing the public of what learning has occurred as a result of complaints, thus demonstrating that complaints are taken seriously and practices/policies have changed as a result
- Greater engagement with community and voluntary groups

9. Suggested Actions to Address Concerns

The HSC Complaints Procedure was developed to ensure that complaints are investigated with a degree of openness and flexibility. In addition, that there are arrangements in place within all Health and Social Care Organisations to ensure that information regarding 'how to make a complaint' is widely publicised with simple, clear guidelines for all areas of the service. However, feedback from the workshop, demonstrates that accessibility and communication are major areas of concern.

1. Awareness Campaign

It is proposed that the Health and Social Care Board in conjunction with the Department of Health Social Services and Public Safety and various Health and Social Care Organisations, develop a communication campaign, to highlight to service users and the general public how to make a complaint and in particular their 'right to complain'. This should include details of what support is currently available and where service users may access additional information. It is suggested that this campaign should last one week, in which various publication mechanisms will be used, to include; radio advertisements; information stalls; the provision of information posters displayed within Family Practitioner premises; the use of social media to include Facebook and Twitter and/or advertisements on Health and Social Care websites.

This campaign will also include information in relation to the various mechanisms which can be used to resolve complaints, in particular, independent medical advisers and/or independent lay persons. It is important to note that the complaints process has a certain degree of independency however greater efforts should be used to ensure that this is widely promoted and that all complainants know that they may access an independent lay person and/or independent expert as part of local resolution. This will reinforce adherence to the Guidance which states that 'HSC organisations will promote the use of independent advice and advocacy services,² which subsequently will ensure that complaints are dealt with promptly, thoroughly, openly, honestly and objectively.

2. Further clarification on the roles and remit of Health and Social Care Organisations.

Recommendation 3 of the Complaints Evaluation outlines that the Guidance should be reviewed to ensure a greater understanding and clarification of Health and Social Care Organisations roles and responsibilities, to include the Regulatory and Quality Improvement Authority and the Patient and Client Council. This issue was further

² Complaints in Health and Social Care – Standards and Guidelines for Resolution and Learning (Page 57)

reinforced at the workshop as service users acknowledged that they were not aware of the availability of the Patient and Client Council and what services they provide to complainants. In addition, it was disappointing to note that those individuals who had used their services felt that they were not fully supported throughout the process. Therefore further discussions will take place between the Department of Health Social Services and Public Safety, the Health and Social Care Board and the Patient and Client Council to review the role and responsibilities of the Patient and Client Council in regards to providing help and support to complainants.

3. Further Service User Workshops

To ensure that a representative sample of the population have had their chance to share their views on the complaints process and to discuss how a regional mechanism to obtain user feedback can be created, it is envisaged that an additional workshop will be held within the Western LCG area in October 2013.

Appendix 1 – Recommendations from the Report on the Process Evaluation of the Complaints in HSC: Standards and Guidelines for Resolution and Learning.

The evaluation identified a total of 14 recommendations which may assist in the further implementation of the Guidance:-

1. The DHSSPS should review the Guidance in order to provide greater clarity in respect of achieving more robust local resolution arrangements in order to ensure a better understanding by staff and service users;
2. The Board should consider co-ordinating training for HSC/FPS staff on a regional basis, as a method to improve the understanding of how more robust local resolution arrangements may be delivered, and improve recognition as to how and when to apply alternative techniques in the resolution of complaints;
3. The DHSSPS should review the Guidance to provide a better understanding and provide clarification to HSC organisations and service users, as to the responsibilities of the various organisations in relation to complaints and more specifically the provision of support and advice to service users wishing to raise a complaint and regarding the sequencing of the complaints process;
4. The Board should, with HSC organisations seek to develop further definition and clarification with respect to the role of the Complaints Manager in order to provide a greater understanding and appreciation by staff and service users of the role in terms of providing support and advice;
5. The Board should remind FPS Practitioners of their requirements under the Guidance and should make tangible efforts to ensure that FPS Practices are aware of and have access to the support and advice that can be provided by the Board in respect of complaints resolution and implementation of the Guidance;
6. The Board should further develop and promote the role of 'honest broker' as a means to resolution of complaints within FPS, in order to provide greater clarity and understanding within HSC organisations, FPS and services users;

7. HSC organisations should ensure that they comply with the Guidance to improve their communications with service users who have made a complaint by developing processes to maintain regular proactive contact with users. This system should include the ability to provide users with a rationale for not being able to respond within the agreed timescales, detail of progress, a projected timescale for completion of investigation and/or timescales for issue of the response;

8. Recognising the practical difficulties in ensuring all staff receive mandatory complaints training, and in an attempt to increase the staff uptake in this requirement, HSC organisations should explore the further roll out of the current e-learning complaints training package. The Board should also ensure that this includes FPS Practices;

9. HSC Organisations and FPS Practices should ensure that where changes to policy procedure, or improvements to services have occurred as a result of a complaint being raised, the service user is informed of this within the response to them, including details regarding implementation of associated actions plans, etc, where appropriate;

10. A regionally agreed method of disseminating learning from complaints should be developed by the Board and Public Health Agency (PHA). This should include the co-ordination of an Annual Regional Complaints Workshop event and agreed adhoc/ scheduled communications, such as Newsletters etc;

11. A regional mechanism for receiving user satisfaction feedback in relation to complaint resolution should be developed by HSC organisations, recognising the sensitivities involved in such an area. The Board/PHA should lead on this with input from the PCC, the Trusts and service users. Consideration should be given to engaging with key stakeholders in this regard through focus groups across the Trust/Local Commissioning Group areas;

12. Recognising that communication, staff attitude and behaviour are among the highest categories of complaints received across the HSC, innovative methods in attempting to address this at the core of staff/service user interactions should be explored led by the PHA and the Board;

13. There may be merit in further regional discussions, led by DHSSPS, regarding the 20 working day response timescale. Any discussions and agreements should include clarification of the timescales associated with honest broker complaints;

14. HSC organisations should review their Complaints Policies and Procedures to reflect any clarification/amendment to the Guidance.