Investigation of a complaint against Belfast Health and Social Care Trust

Report Reference: 202001744

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The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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SUMMARY

I received a complaint that the community care provided to a young woman with learning difficulties and a severe physical life-limiting condition failed when she transitioned between the Belfast Health & Social Care Trust's (the Trust) Children's and Adult Community Services. Through her childhood years the Trust oversaw an effective care package delivered by two independent providers, with an element of care funded via Direct Payments[1]. When the young woman (the service user) transitioned to adult care, the Trust dismantled the existing package in favour of a new contract with a nursing provider. The complainant (her mother) who had wanted the existing arrangements to continue, said the change resulted in a significant fall in the standard of care, causing distress and anxiety to both her daughter and herself, the principal carer.

I was surprised to find the Trust dismantled an effective care package that had been in place for several years, one which had operated very effectively, despite the significant level of care that was needed to maintain the service user's health and happiness. I consider that any interruption to the care of a highly dependent service user has the potential to cause huge stress and anxiety among the service user's closest loved ones, not to mention the obvious distress caused to the service user.

I was further surprised to find a gap in the Trust's policy and procedures for governing the process as the Trust admitted that *'unfortunately there do not appear to be any policies and procedures in Children's or Adult Services in relation to Transitioning to Adult Services.*' This represents a significant and unacceptable gap and one which requires to be remedied urgently.

I further found the Trust failed to engage in the process of transition as early as it should have done. The earliest record the Trust provided of Adult Services involvement in the service user's case is dated one month before the service user's 18th birthday. I noted

[1] Direct payments are local Health and Social Care Trust payments for people who have been assessed as needing help and, would like to arrange and pay for their own care and support services instead of receiving them directly from the local trust.

that this transition was not a movement between different organisations but simply across two different teams within the Trust. I considered opportunities were lost for decision makers to build relationships with the service user and her family, and to observe how care was being delivered, in order that appropriate health professionals might be fully informed when assessing risks in care provision.

The investigation also found care plans that were incomplete and insufficient at the commencement of the new care package and many gaps in documentation.

I concluded there were a number of failures in the care and treatment provided, and those failures caused the injustice of lost opportunity, distress and anxiety for the service user, the complainant, and the other immediate family members over several months. Sadly, due to the subsequent death of the service user, those disruptive and anxious months were among the last that the family had with their precious daughter and sister.

I recommended that the Chief Executive apologised to the complainant in writing. I also recommended that the Trust developed policy and procedures to govern the transition between child / adult services, both to fill the existing gap in policy and to ensure this challenging time of change is managed sensitively, empathetically, and as effectively as possible for service users and their families.

Finally, I recommended an audit of a sample of care records for service users currently under the care of adult community services, with the findings to be provided to my office.

THE COMPLAINT

1. This complaint was about the Belfast Health & Social Care Trust's (the Trust) planning / management of a service user's transition between its Children's and Adult Community Services in the summer of 2019. The complainant was the service user's mother.

Background

2. The service user had a neuro-degenerative disorder which was a severe physical life-limiting condition. She also had epilepsy, scoliosis, osteoporosis, sight impairment and a learning difficulty. The service user was enteral[2] fed and needed oxygen therapy. Over a period of years, frequent suctioning (oral and nasopharyngeal) was a necessary part of the care regime to ensure the service user's airway was kept clear of mucous and to reduce the risk of chest infection.

3. The Trust was responsible for the provision of a long-term substantial care package to meet the service user's needs within her home and school environments.

4. The complainant had selflessly cared for her daughter at home for many years. For the several years preceding the transition to the Trust's Adult Community Services, the complainant had enjoyed a positive experience in terms of the substantial support she received via a care package organised by the Trust's Children's Community Services and delivered by Health Care Assistants, with support from carers employed directly by the complainant via Direct Payments[3].

5. The service user reached 18 years of age on 22 February 2018 at which point her care formally became the responsibility of the Trust's Adult Community Services.

Issue of complaint

6. I accepted the following issue of complaint for investigation:

[2] Delivering nutrition directly to the stomach or small intestine via a tube.

[3] Direct payments are local Health and Social Care Trust payments for people who have been assessed as needing help and, would like to arrange and pay for their own care and support services instead of receiving them directly from the local trust.

Whether the Trust adequately managed the service user's transition from Paediatric to Adult Services in order to ensure the service user's ongoing complex care needs were met.

INVESTIGATION METHODOLOGY

7. To investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with its comments on the issues the complainant raised.

Independent Professional Advice Sought

8. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisors:
    - a social worker with 34 years of experience across children's and adult services (ISWA); and
    - a senior nurse with 19 years of experience in community nursing including managing transitions of children with nursing needs into adult services (Nurse IPA).

9. The information and advice which informed the findings and conclusions are included within the body of this report. The IPAs provided *advice*. However, how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards and Guidance

10. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those specific to the circumstances of the case. I also refer to relevant regulatory, professional, and statutory guidance. The general standards are the Ombudsman's Principles[4]:
    - The Principles of Good Administration

11. The specific standards and guidance referred to are those which applied at the time the events occurred. These governed the exercise of the administrative functions and professional judgement of those individuals whose actions are the subject of this complaint.

[4] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

12. The specific standards and guidance relevant to this complaint are:

- Disabled Persons (NI) Act 1989 (Disabled Persons Act);
- The NI Commissioner for Children and Young People's Review of Transitions to Adult Services for Young People with Learning Disabilities, September 2012 (NICCY Review);
- The Department of Education's *Code of Practice on the Identification and Assessment of Special Educational Needs*, September 1998 (DE Code of Practice);
- NIPEC[5] Decision to Delegate: A Decision Support Framework For Nursing And Midwifery, January 2019 (Delegation Framework);
- NMC[6] The Code - Professional standards of practice and behaviour for nurses, midwives and nursing associates, 2018 (NMC Code of Conduct);
- NICE's[7] guideline on Transition from children's to adults' services for young people using health or social care services, February 2016 (NICE NG43);
- The Department of Health's[8] *Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs*, May 2009 (Integrated Care Pathway) and
- UK Government Legal Department's *The Judge Over Your Shoulder* guidance, July 2022 (Government decision-making guidance).

Reference to the standards and guidance is made within the IPA advice.

13. I did not include all information obtained during the investigation in this report. However, I am satisfied I took into account everything I considered relevant and important in reaching my findings.

14. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations.

[5] Northern Ireland Practice and Education Council for Nursing and Midwifery
[6] Nursing and Midwifery Council
[7] National Institute for Health and Care Excellence
[8] Then called the Department of Health, Social Services and Public Safety

THE INVESTIGATION

Issue:

Whether the Trust adequately managed the service user's transition from Paediatric to Adult Services in order to ensure the service user's ongoing complex care needs were met.

Detail of Complaint

15. The complainant said the care package which the Trust's Children's Community Services organised for the service user, had been *'efficiently provided'* over a period of several years, until the end of June 2019. Mindful of the complexities of her daughter's care, the complainant wanted this set-up to continue. Instead, she was *'forced to have a nursing agency to replace [the] existing carers'.* The complainant said service provision for her daughter deteriorated under the new arrangements.

16. The complainant said when her daughter transitioned to Adult Community Care, the Trust '*failed to deliver adequate care for [her] daughter.'*

17. The complainant said the Trust *'failed to recognise the poor / lack of communication between BHSCT[9] departments that in turn caused [a] high level of distress and disservice.'*

18. The complainant raised other issues in relation to the attitude and competence of staff and these included:
    - whether the Trust acted appropriately when the complainant raised concerns about the competency of a named nurse employed by the nurse provider;
    - the effect (if any) on parental control when a service user transitions from Children's to Adult Services; and
    - what a Trust should tell a service user's family (in similar circumstances) where there is a risk to the continuity of community care provision.

[9] Belfast Health & Social Care Trust

Evidence Considered

Legislation/Policies/Guidance

19. I considered the following legislation/policies/guidance:

- Disabled Persons Act;
- NICCY Review;
- DE Code of Practice;
- NMC Code of Conduct;
- Delegation Framework;
- NMC Code of Conduct;
- NICE NG43;
- Integrated Care Pathway; and
- Government decision-making guidance

Trust's response to investigation enquiries

20. The Trust apologised that *'the Transition to Adult Services was not as seamless as we would aspire to, due to issues with governance, training, and updating competencies which were specific to [the service user's] needs.'*

21. The Trust said *'unfortunately there do not appear to be any policies and procedures in Children's or Adult Services in relation to Transitioning to Adult Services.'*

22. The Trust said it has been *'scoping policies and procedures for training in nasopharyngeal suction in the wider physiotherapy service with the Belfast Trust and regionally, and this work is ongoing.'* The Commissioned Service Manager *'will continue to escalate this to the Trust Senior Governance Meeting as an unmet need.'*

23. The Trust said it is *'very unusual'* for children with both a learning difficulty and a severe physical life-limiting condition to reach adulthood and its adult learning disability team therefore *'had no previous experience of caring for a service user with [the service user's] clinical needs.'* The Trust categorised the service user's case as 'unique' because she had *'a severe physical life limited condition alongside her learning disability when she transitioned into Adult Services.'*

24. The Trust said:
'The process commenced at the appropriate time but unfortunately this is an unprecedented case and we were unaware that there would be an issue with accessing nasopharyngeal suctioning training.'

25. The Trust said when the service user transitioned to *'Adult Learning Disability [ALD] Services'* a *'Transitions Physiotherapist'* (Band 7) post had not been established. The post was filled on 6 January 2020.

26. The Trust said the first assessment of the service user's needs by the ALD Physiotherapy team, on 5 April 2019, noted that *'oral and nasopharyngeal (NP) suction were undertaken by trained staff and mum, but as the Paediatric Physiotherapy service was not involved in [the service user's] respiratory management, it was not identified as a physiotherapy need at that time.'*

27. The Trust said, subsequently[10], the complainant asked *'if the ALD Physiotherapy team could offer suction training to [the Nursing Provider's] staff.'* Following this request*, 'the ALD community and Acute Paediatric physiotherapy teams worked closely together to organise NP suction training.'*

28. The Trust said:
'The usual process when the Trust commissions a Nursing Agency is that the Agency provides training for their staff in the required competencies. It appears that [the Nursing Provider's] staff tried to access NP training but because it is rarely used in Adult Services, they were unable to do so which resulted in a delay accessing training. A referral was then made to physiotherapy requesting assistance with this issue in October 2019.'

29. The Trust said that because nasopharyngeal suction is rarely used in Community Adult Services *'Trust wide'*, there are *'no set care pathways and protocols in place.'*

30. The Trust said the service user's *'care needs were initially assessed in April [2019] by the ALD community staff in post at that time, but the issue regarding training new*

[10] Physiotherapy record dated 31 October 2019.

staff on NP suction was only raised 6 months later.'

31. The Trust said the *'development of the Transitions Physiotherapy Post should ensure that all physiotherapy needs [are] identified in a timely manner, going forward.'*

32. Training for the nursing provider's *'Lead Nurse and [Adult] community physiotherapist'* was provided by the *'paediatric physiotherapy trainer'*. The Trust said that due to the availability of the trainer, there was a delay in suction training, the first session not taking place until 20 December 2019. The Trust said the process for signing off the competencies of the staff involved was slow because the service user's need for suction had decreased at that time.

33. The Trust said the nursing provider's staff were due to be phased in from 8 July 2019. However, the service user's mother asked that this be postponed until after the summer to accommodate family holiday plans.

34. The Trust said the complainant requested that *'only nursing staff would commence shadowing at nights'* and *'shadowing by Health Care Assistants (HCA) staff was requested to be put on hold'*, which both the Trust and the nursing provider facilitated.

35. The Trust said delay in confirmation of the complainant's holiday arrangements contributed to delayed completion of the nursing provider's training.

36. The Trust said a breakdown in the relationship between the complainant and the nursing provider's staff, including the lead nurse, meant that *'on occasions'* cover could not be provided.

Relevant Trust records

37. The Trust provided a substantial set of records which covered the period from January 2018 to September 2020, the month in which the service user died. These records covered nursing and physiotherapy notes, notes made by independent care providers and tendering records relating to the new nursing care package decided upon by the Trust.

Relevant Independent Professional Advice

38. The ISWA advised that the transition process:
'should have been well-planned, initiated in advance of the date of transition and should have enabled a smooth handover between Children's and Adult Services, with the minimum possible disruption to gaps in the service user's service provision and that the views and wishes of the service user and/or her family ought to have been as central to the process as possible.'

39. Referring to the '*complexity'* of the service user's condition, the ISWA advised that *'there should have been early discussions with Adult Services about how her needs were going to be met'.* In relation to a child with a Statement[11] which the service user had undoubtedly been, the ISWA noted that the DE Code of Practice identified the age of 14 years as significant in relation to triggering transition planning for a child as they progress into adulthood. The ISWA advised that, from that age, the responsible Education Board[12], should seek an opinion from the child's Health and Social Care Trust as to whether the child may require health services from the Trust when leaving school. The ISWA advised that section 5 of the Disabled Persons Act provided the statutory basis for this requirement.

40. The ISWA advised of the relevance of the NICCY Review, a comprehensive report which addressed the issue of transition to adulthood, as it applies to *'young people with learning disabilities*.' The ISWA quoted a list of factors, drawn from research, that make for a '*successful'* transition. Among these, she highlighted *'a good knowledge transfer infrastructure between child and adult services'* as being required.

41. Noting the Trust had confirmed the *'absence of any formal policy or procedural framework within the Trust to govern the transition process'*, the ISWA said this was *'less than ideal'* and advised that this was a barrier for families in terms of understanding the process.

42. The ISWA identified a PARIS[13] record dated 25 November 2019 which was completed by the lead nurse employed by the nursing provider. It records that at

[11] Statement of Special Educational Need
[12] Now the Education Authority
[13] Patient Automated Record Information System

the commencement of the contract she had informed both the Trust and the complainant that there were no care plans that covered '*vest physio'*, '*chest physio'*, *'standing frame'*, *'chest brace'*, '*feeding regime'* and, *'no medication kardex'.*

43. The Nurse IPA advised that care plans which had been provided to the investigation were incomplete and insufficient in the areas of care they covered.

44. The Nurse IPA listed several reasons why transitions between children's and adult services are challenging. She advised that, therefore, where the service user has *'very complex needs'*, it is '*imperative'* for adult services to have substantial engagement with the service user at an early stage. The Nurse IPA advised that engagement did not occur soon enough in this case.

45. The Nurse IPA advised that *'there could have been a lot more preparatory work for the transition of this service user.'* The advisor highlighted the importance of establishing an early relationship with family members to ensure the '*constraints'* and differences in an adult health care package were outlined. The Nurse IPA highlighted the importance of the adult team *'familiarising themselves with the care required at least when the service user turned 18 . . . to understand . . . the risks associated with [her] care.'* The Nurse IPA advised there were *'many gaps'* in the documentation.

46. The Nurse IPA referred to the Delegation Framework as the predominant basis upon which the Trust decided to replace the existing independent care provision with a nursing provider. Referring to the *'decision support matrix'* (page 12) the Nurse IPA advised *'Nasopharyngeal suctioning is a task that could fall into the category of high risk if not done correctly or the decision of whether to suction or not carries a high level of responsibility.'* The Nurse IPA advised it is not clear from the records whether this aspect of the Delegation Framework provided the basis for the decision.

47. The Nurse IPA advised that the NMC Code of Conduct would have supported such a decision, if this was the basis for the decision. However, the IPA added that the complainant's ability to suction her daughter safely and, arguably, that of the carers who had worked with the service user for a few years, points to the risk being *'very low'* in this instance. The Nurse IPA advised that *'had the adult team been more*

involved with getting to know the service user and her needs in the year between her 18th and 19th birthday this decision-making process could have been different.'

48. The Nurse IPA advised that the *'tendering document was adequate and had the skills outlined in enough detail to attract the right staff via the right agency to supply the care package.'* However, referring again to suction, the IPA noted that *'staff would still have to be signed off as competent with that service user since nasopharyngeal suctioning is not something that is commonly used with older adults.'* The Nurse IPA advised the *'main stumbling block'* with the new care package was *'education, training and competency sign off for nasopharyngeal suctioning.'*

49. The Nurse IPA noted the complainant's actions when the Trust *'insisted on the old care package ending'*: attempts at delaying the changeover; not permitting new staff to '*train'* on her daughter; and suggesting a shared care package to allow her to continue to use her direct *payments 'to get some respite over the weekends and some nights'*. The Nurse IPA advised that *'it may have been easier to move forward had there been consideration of that request.'*

50. The Nurse IPA advised *'the main failure of the Trust is the absence of any substantial engagement at an early date regarding the transition of somebody who clearly had very complex needs.'* The IPA advised *'the documentation presents a family that is both frustrated with a system that feels new to them and are also frightened for their daughter.'*

51. Both the ISWA and Nurse IPA advised that when a child reaches maturity, the parents lose overall responsibility for best-interest decision-making. At that point a parent's view is considered in tandem with the views of relevant health professionals to determine what is in the best interest of a service user who does not have capacity.

52. In circumstances where there is a risk of a care package failing, both the ISWA and the Nurse IPA advised of the need for the health authority to communicate its honest appraisal of the potential consequences of there being an interruption to care provision, and possible solutions. The ISWA advised this should be handled with empathy and sensitivity.

Response to draft investigation report

53. The Trust offered no comment on the draft investigation report.

54. The complainant said: *'Because of [her daughter's] medical condition, the change in the care package and consequent fall in the standard of care, [she] believe[d] that [her daughter] was placed at high risk of harm.'* This was the complainant's main concern.

55. The complainant said her daughter *'was assessed as needing chest therapy and suctioning'* from 2009. She indicated that the Trust's long-term knowledge of her daughter's respiratory needs should have been appropriately used in the period before transition.

56. Referring to the Nurse IPA advice, the complainant asked whether the Trust acknowledged the need for policies and procedures in relation to transitioning.

57. The complainant referred to page 39 of the draft report where the ISWA quoted a Trust record, dated 11 October 2019, which committed to following up on *'training regarding nasal suctioning with the physio service'.* The complainant said the training was not put in place until 10 January 2020.

58. The complainant listed several aspects of the ISWA report with which she did not agree. These have been noted.

Analysis and Findings

59. The service user faced significant health issues. The Trust said that it was *'very unusual'* for a child with a severe physical life-limiting condition alongside a learning difficulty to reach the stage of transition to adult care as, *'unfortunately many die before the age of 18.*' The Trust categorised the service user's case as '*unique'.*

60. The service user undoubtedly had strength and resilience, and she reached adulthood despite the constant threat posed by her health. This is testimony to the resolve of the service user, but also to the love and support provided by her family

and the other care providers involved. The complainant expressed her admiration for the able care team that had cared for her daughter over many years. Carers who got to know the service user well and were experienced in providing for her daily needs. Health care assistants built up experience of caring for the service user's complex needs and often became valued friends who, given their competencies, were trusted to deliver the service user's care. I appreciate that this enabled her mum and other members of the immediate family to take much needed respite. Trust, partnership and good communication are key elements of ensuring appropriate support.

61. Carers who were not employed by the Trust were supported and trained on an ongoing basis by a team of health professionals from the Trust's Children's Community Services, including community nursing staff, physiotherapists and social workers. The Trust played a pivotal role in managing the service user's care package. I consider that, to a large degree, it is reasonable to attribute the maintenance of the service user's health to the standard of care she received. The Trust and the independent care providers should be commended for the part they played in caring for the service user through her childhood years.

62. Given this apparent success story, I was surprised to find the Trust dismantled an effective care package that had been in place for several years. One which had operated very effectively, despite the significant level of care that was needed to maintain the service user's health and happiness. I consider that any interruption to the care of a highly dependent service user, has the potential to cause huge stress and anxiety among the service user's closest loved ones, not to mention the obvious distress caused to the service user themselves.

Early engagement

63. The service user's needs were complex, and I acknowledge her transition between children's and adult services was therefore complicated. I accept the transition was not a straightforward matter. However, I am concerned to note how poorly this transition was planned and implemented. This was not a transition from one Trust to another or one organisation to another which may have brought more complexity. This was transition within the same organisation, the Belfast Trust, from one team to another and it is of concern that this appears to have proved so difficult for these

teams to effectively share knowledge and engage with the service user and her family. The long-term nature of the service user's care gave the Trust valuable knowledge and experience of her needs. I consider this resource would have been very useful for planning the delivery of an effective transition; one which was as unobtrusive and unsettling as possible for the service user and her family. I consider it was reasonable for the service user and her family to expect an effective transition, irrespective of whether the Trust viewed her case as '*unprecedented'* or '*unique'*.

64. The service user *'had little or no communication'* and so understanding her needs and her mood was challenging for carers, though this would improve over *'several months/years'* as carers *'got to know her well, when she's well and when she's not, when she's not great but she's ok or when she's not her usual self.'* For example, in comments attributed to the complainant, '*clammy'* skin may have meant the service user was upset, as opposed to suffering from a fever. According to the complainant, the existing carers knew her daughter *'inside out'* and were tuned into her subtle communications, body posture and eye contact.

65. I consider that, in the months and years before transition, there was an obvious necessity for adult community services staff to take a developing interest in the service user's case and begin to consider how her needs could be met after transition. The DE Code of Practice points to the necessity of engagement from the age of 14. The NICE guidance NG43 refers to year 9 (age 13 or 14). The Integrated Care Pathway states that planning should commence *'around the young person's 14th birthday or earlier as required.'* Both the ISWA and the Nurse IPA advised of the importance of early engagement. I accept this advice.

66. For reasons that are obvious, the complainant requested that the existing care package should continue. However, several weeks before the new care package was due to commence, the Trust informed her that *'with regard to the ongoing training of staff'* there was *'no similar resource within the Adult Learning Disability Programme'* to accommodate continuance of the existing package. The Trust subsequently informed this office that '*we were unaware that there would be an issue with accessing nasopharyngeal suctioning training'.* I consider that these issues could and should have been identified and addressed sooner, had there

been the earlier engagement indicated by the IPAs and the guidance.

67. I consider the years before the service user's 18th birthday also presented a valuable opportunity for staff from the adult team to build relationship and trust with the service user's immediate family, an important consideration given the changes to parental control that lay ahead. The Nurse IPA advised of the change to parental control that occurs when a child in these circumstances becomes an adult. She advised of the anxieties which the loss of control can often create for parents in terms of the perceived increased risk to their child. I accept this advice and I consider there was therefore a need for Adult Services to anticipate these difficulties and, in the months and years before transition, to ensure relevant staff were beginning to develop relationships and build trust with the service user and her family. I did not find evidence of this.

68. The earliest record the Trust provided of Adult Services involvement in the service user's case, is dated 19 January 2018, one month before the service user's 18th birthday. The internal meeting was held to plan the service user's transition to adult care. I sought evidence of earlier involvement but, to date, the Trust has not provided any further documentation. In the absence of any further evidence, I consider this was a missed opportunity.

69. The Nurse IPA also advised that it was reasonable to expect health professionals from the Adult Services team to take the opportunity to see first-hand the delivery of the service user's care under the set-up run by the Trust's Children's Services. The Nurse IPA advised that the shadowing of care provision by health professionals would have enabled Adult Services to better assess whether the risks associated with the service user's care, for example, the suction procedure, were acceptable. According to the complainant suction was a daily procedure, being required three times per day on a '*lucky'* day but, sometimes several times per day and during the night. I accept the need for suction may have varied but I am satisfied it was sufficiently common for carers to maintain competence in the procedure during the service user's childhood years.

70. The Nurse IPA advised that shadowing care provision would have enabled Adult Services to better assess the level of risk posed by continuing with the existing unqualified but trained carers who knew the service user, for continuity. I accept

this advice. I consider it would also have provided a further opportunity for Adult Services to address the issue of training provision going forward. I did not find evidence of this approach and I consider this was a further missed opportunity for productive engagement with the family.

71. The Nurse IPA provided helpful advice on the value of early engagement and the potential opportunities it would have presented to enable the Trust to better assess the risks of continuing with the existing set-up and considering the complainant's request for a shared arrangement to include a Direct Payments element. There was no doubt in the complainant's mind that dismantling a successful care package which was working well for all parties, and had done so over several years, was far from being the best option to support both she and her daughter. Before the transition, the complainant made what I consider to be a compelling case which demonstrated the additional pressures and stresses which the proposed substantial change would place on her daughter, herself and the immediate family.

72. I acknowledge that it was the Trust's responsibility to assess the risks and make the decision; the Trust had the discretion to decide what was best for the service user. However, whilst the Trust said '*the process commenced at the appropriate time',* I do not accept this to be the case and, I am satisfied the Trust's Adult Services team did not engage with this case as early as they should have done. I accept the IPA advice that early engagement and observation of the existing set-up would have assisted with an analysis of the options and the risks associated with each. It would also have assisted with the identification of gaps in training provision.

73. Taking account of this advice supported by the available guidance, I consider the Trust's Adult Services failed to engage with the service user soon enough to begin the process of transition which, I consider, is a failure in the care and treatment of the service user. It is not that the challenges that arose would necessarily have been avoided, but I consider that, with earlier engagement, the Trust would have been better prepared to meet them. I am satisfied that the failure to engage sufficiently early, was therefore a missed opportunity for the service user and her mum to transition to Adult Services with less of the distress, upset and anxiety that arose as a result of the transition. While the responsibility for best interest decision making may have changed with the transition to adult services, this should not

change the approach which should always be based on involving family members and listening carefully to their views.

Policy and procedure

74. The provision of health care for children is not the same as that for adults. There is a difference in funding. The Nurse IPA advised that, in comparison to an adult, there is *'a larger pool of funding available'* in relation to care packages for children with needs similar to that of the service user. I understand this difference is a long-standing aspect of health care provision which is applied generally within the UK.

75. There is also a difference of responsibilities. Throughout childhood, it is the parent who has the responsibility for looking after their child's health care. The parent has the autonomy to decide what is best for their child. The Nurse IPA advised parents are in *'full control'*. However, when the child reaches the age of 18 years, that responsibility shifts, effectively overnight, to the health authority, in this case the Trust. Although their views are still considered to be a key part of the decision-making process, the parents *'lose the control that they have had'*. The Nurse IPA advised that parents *'often feel that this is incredibly risky for their child.'*

76. The Nurse IPA highlighted other areas affecting care provision that can be impacted when a child transitions to adult care services: delegation, equipment, input within care packages and, processes. I accept this advice which I consider makes clear that the transition between children's and adult services can present significant challenges for the families of those without capacity who are in receipt of continuing care. I consider there are substantial issues which have the potential to impact care delivery at transition between child and adult services.

77. Moreover, I note that, in November 2016, the Department of Health estimated that around 1300 children were living with life limiting conditions in Northern Ireland[14]. I consider it is likely this figure was higher in 2019, and indeed higher again in 2023. As early as 2009, the Integrated Care Pathway, then introduced by the Department[15], acknowledged the number of service users transitioning between children and adult services would rise as life expectancy increased.

[14] A Strategy for Children's Palliative and End-Of-Life Care 2016-26

[15] Then called the Department of Health, Social Services and Public Safety

78. In light of the data and the significant challenges that transition brings, I was surprised to find the Trust had *'no policies and procedures in Children's or Adult Services in relation to Transitioning to Adult Services.'* The fourth Principle of Good Administration requires public bodies to act *'fairly and proportionately'*. Government decision-making guidance includes that it is *'essential for fairness and consistency in decision making, for decision makers to have a policy'*. The Nurse IPA advised *'the lack of policies and procedures covering this area would add to the challenges that already exist when working with children and families who go through the transition process.'* The ISWA also advised this was '*a barrier for families in terms of understanding the process.'* I accept this advice. Taking account of the guidance and the advice, I consider the lack of written policy and procedure in this case constituted maladministration.

79. I note the Trust has recognised there is a need for policy development in this area and further note the Trust's assurances that it has undertaken a *'scoping of policies and procedures'* in a particular area of training for the wider physiotherapy service. However, noting the complainant's concerns, I consider a broader review is necessary in the general area of transitioning between children's and adult services. I will refer to this further in the conclusion of this report. However, the Trust may find the examples highlighted by the advisors as a helpful benchmark.

80. I note the Trust recognised the transition had not been executed as well as it should have been and apologised to my office. I will address the question of the recommended remedy in the conclusion of this report. The Trust explained that it had *'issues with governance, training, and updating competencies which were specific to [the service user's] needs.'* I consider these important areas will feature in the Trust's development of policy and procedure as a result of this case.

81. Communication is a similarly important area which is a relevant policy consideration. The complainant claimed that the Trust *'failed to recognise the poor / lack of communication between BHSCT[16] departments that in turn caused [a] high level of distress and disservice.'*

[16] Belfast Health & Social Care Trust

82. I note that, from October 2019 the Adult LD Physiotherapy discipline had a role in providing NP suction training to the nursing provider's staff. An earlier assessment of the service user's needs on 5 April 2019 had noted NP suction as a need but taken no action. The Trust explained:
'It was noted that oral and nasopharyngeal (NP) suction were undertaken by trained staff and mum under the existing care package, but as the Paediatric Physiotherapy service was not involved in [the service user's] respiratory management, it was not identified as a physiotherapy need at that time.'

83. This explanation raises a question about internal communication because the existing care package was soon to end (June 2019) and the plan was to appoint a nursing provider to perform this procedure. I have already addressed the issue of transition planning above. This is a further example which does not inspire confidence that transition planning was adequate.

84. Also, although the suction-training needs of the nursing provider's staff materialised as soon as the new staff began to shadow existing carers (July 2019) the communication of that need appears confused, since that team did not become involved in organising the provision of training until October 2019, four months later. Moreover, there is no evidence of this problem being anticipated beforehand, even though the requirement in adults for '*frequent'* NP suction was '*extremely rare'*.

85. I consider these issues are linked to the failure to have written policy and procedure for transition between children and adult services, identified in this section.

Care plans

86. The ISWA said she was *'unclear as to why all care plans had not been completed and signed off much earlier than they were, in readiness for the supposed commencement date'*. I examined the care plans provided to NIPSO by the Trust. These covered: 'Moving and handling', 'Feeding', 'Continence', 'Nasal suction', 'Breathing and tracheostomy care', and 'Personal care'.

87. The titles differed to those noted in the PARIS record quoted in the ISWA's report, though they appeared to cover similar ground. However, they were all dated prior to July 2019 when the new care contract had been due to commence. On closer examination, there was no indication that these care plans had been *'discussed and*

agreed with the patient/carer' or reviewed. Moreover, one care plan referred to *'tracheostomy care'* which was not relevant to the service user. The Nurse IPA advised these care plans had not been adequately completed. The IPA referred to other care plans that should also have been produced covering, for example, communication, accessing the community and, spiritual needs.

88. I note the PARIS note quoted in the ISWA's report also records the absence of a medication Kardex at the commencement of the contract. The Nurse IPA advised of the importance of a Kardex to record prescribed medications and when they had been administered. I accept this advice and appreciate the necessity of this medical record to ensure the adequacy of the service user's care.

89. I consider these findings are indicative of a failure in the service user's care and treatment. I am satisfied this caused the service user and her family the injustice distress and anxiety over the standard of care that was being delivered.

Trust's handling of the competency of non-Trust staff

90. The complainant alleged that a particular member of the nursing provider's staff lacked competence. The complainant referred to '*errors'* made by the nurse which she considered ultimately placed her daughter at risk. This issue did not relate to the Trust's staff but rather the staff of a provider contracted to provide a service on behalf of the Trust. It should be noted that this office does not consider staff disciplinary issues. However, I undertook to establish whether the Trust acted appropriately when the competency issues were brought to its attention. Both the ISWA and the Nurse IPA advised that the Trust had acted appropriately by raising the matter with the nurse's employer for consideration / further action. I am satisfied this was in order.

Communication where there is a risk to continuity of care

91. The complainant said she felt threatened at a meeting held on 24 December 2019, at which the continuity of the service user's care was discussed in a scenario where the nursing provider was unable to continue providing the service. During the meeting, the Trust advised the complainant that her daughter may have to be placed in residential care if certain issues with the care package could not be

resolved. The complainant was concerned by the '*tone'* in which this information was communicated.

92. Although I am unable to verify the manner in which any communication may have been voiced at the meeting, I sought independent advice in relation to what the Trust should tell the family of a service user in these circumstances.

93. Both the ISWA and Nurse IPA advised the best approach is to be honest and supportive in relation to the risk of discontinuance, and the Trust should outline options to ensure care provision can continue to give a positive outcome for both the service user and her family. I consider such discussions are often emotive and so it is imperative that those participating do so in a professional manner, with compassion, having regard to the challenging circumstances the service user and her family are facing.

94. Given the previous care package had been working effectively, it is disappointing and concerning that, by December 2019, the circumstances were such that the possible need arose for a move to a care home. I refer to the earlier analysis in relation to appropriate planning, engagement, communication and trust.

CONCLUSION

95. I received a complaint about the Trust's planning / management of a service user's transition between its Children's and Adult Community Services in the summer of 2019. I upheld elements of the complaint for the reasons outlined in this report. I consider there was a failure in the Trust's care and treatment of the service user. I also found maladministration in relation to the absence of policy and procedure to govern transition between children's and adult community services.

96. I recognise the failures caused the service user, her mum and the immediate family the injustice of lost opportunity, distress and anxiety.

97. I offer through this report my condolences to the complainant and her family for the loss of their precious daughter and sister soon after the events covered by the complaint.

Recommendations

98. I recommend the Trust provides to the complainant a written apology in accordance with NIPSO's 'Guidance on issuing an apology' (July 2019), for the injustice caused as a result of the failures identified (within **one month** of the date of this report).

99. I further recommend the Trust's current scoping of policy is broadened to encompass the general area of transition between Children and Adult Services (for service improvement and to prevent future recurrence). The resulting policy / policies should be forwarded to NIPSO when complete. The Trust should provide this office with evidence that this investigation report has been shared at the appropriate Trust governance level.

100. I further recommend that an audit of a sample of care plans and medication Kardex's for service users currently under the care of adult community services is conducted within the next six months and the results provided to this office with details of findings and any necessary remedial action taken.

101. The Trust should implement an action plan to incorporate these recommendations and should provide me with an update within six months of the date of my final report. The Trust should support its action plan with evidence to confirm it took appropriate action (including, where appropriate, records of any relevant meetings, training records and/or self-declaration forms which indicate that staff read and understood any related policies).

MARGARET KELLY
Public Services Ombudsman **August 2023**

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Appendix Two

PRINCIPLES OF GOOD COMPLAINT HANDLING

Good complaint handling by public bodies means:

Getting it right

- Acting in accordance with the law and relevant guidance, and with regard for the rights of those concerned.
- Ensuring that those at the top of the public body provide leadership to support good complaint management and develop an organisational culture that values complaints.
- Having clear governance arrangements, which set out roles and responsibilities, and ensure lessons are learnt from complaints.
- Including complaint management as an integral part of service design.
- Ensuring that staff are equipped and empowered to act decisively to resolve complaints.
- Focusing on the outcomes for the complainant and the public body.
- Signposting to the next stage of the complaints procedure, in the right way and at the right time.

Being customer focused

- Having clear and simple procedures.
- Ensuring that complainants can easily access the service dealing with complaints, and informing them about advice and advocacy services where appropriate.
- Dealing with complainants promptly and sensitively, bearing in mind their individual circumstances.
- Listening to complainants to understand the complaint and the outcome they are seeking.
- Responding flexibly, including co-ordinating responses with any other bodies involved in the same complaint, where appropriate.

Being open and accountable

- Publishing clear, accurate and complete information about how to complain, and how and when to take complaints further.
- Publishing service standards for handling complaints.
- Providing honest, evidence-based explanations and giving reasons for decisions.

- Keeping full and accurate records.

Acting fairly and proportionately

- Treating the complainant impartially, and without unlawful discrimination or prejudice.
- Ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case.
- Ensuring that decisions are proportionate, appropriate and fair.
- Ensuring that complaints are reviewed by someone not involved in the events leading to the complaint.
- Acting fairly towards staff complained about as well as towards complainants.

Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Providing prompt, appropriate and proportionate remedies.
- Considering all the relevant factors of the case when offering remedies.
- Taking account of any injustice or hardship that results from pursuing the complaint as well as from the original dispute.

Seeking continuous improvement

- Using all feedback and the lessons learnt from complaints to improve service design and delivery.
- Having systems in place to record, analyse and report on the learning from complaints.
- Regularly reviewing the lessons to be learnt from complaints.
- Where appropriate, telling the complainant about the lessons learnt and changes made to services, guidance or policy.