Clinical Advice Form

Clinical Adviser

I set out below my request for clinical advice.

The complainant and their relationship to the patient

The Complainant ("Mrs O") is the mother of ("AO")

The complaints by Mrs O subject to investigation

a) The delay between her daughter's autism diagnosis and her first appointment with the Integrated Autism Service ("IAS") in 2018.

b) Her daughter receiving more than 1 "initial appointment" with the IAS.

c) The level and quality of support her daughter received from the IAS which the Service Manager IAS acknowledged in her letter to Mrs O's daughter in June 2020 had been "disappointing".

d) The level of support Mrs O received from IAS.

Areas that I am not expecting the Adviser to comment on

- Complaint handling

Background and the events

Mrs O approached the Ombudsman's office in September 2020. As part of an initial settlement the Health Board was asked to provide a chronology of events. Mrs O was dissatisfied with the information provided and has again questioned the care provided by the IAS.

Mrs O in her complaint is dissatisfied with the 6-month delay in her daughter initially being seen by the Psychologist and she comments that 3 of the appointments she had were classed as initial appointments and that this extended over a 22-month period. She contrasts the support she received initially with the support provided more recently. Mrs O has referred to NICE guidelines and believes that the IAS failed to follow the guidelines on the care, support and treatment to be provided to people with autism and their families.

In setting out the background events, I have relied primarily on the IAS case records only – although I note that Mrs O does not feel that the records are an accurate reflection of the contact that she had with IAS.

I note from the case records regarding AO that it says that the referral from AO's GP was received on 4 July **2017** and accepted on 25 July. AO had a post diagnostic session with Dr Y the Psychologist on 30 August **2018** where AO's extended period of low mood, anger towards her mother and self injurious head hitting/punching was documented.

AO was directed to her GP for support for her low mood and the Psychologist discussed talking therapy. Mrs O subsequently made contact to say that the Local Primary Mental Health Support Service ("LPMHSS") had not accepted the GP referral and had referred her back to IAS, although this subsequently changed. During Mrs O's telephone call with Dr Y on 4 December there is reference to her saying that college was going brilliantly for her daughter and that she was making friends. [As part of her complaint Mrs O has referred to this discussion and sought to provide context to how AO was at home as part of her complaint]. AO's management going forward was discussed and the records note that AO was to be moved to the support waiting list and a letter to confirm this sent to Mrs O.

The Psychologist spoke to Mrs O in February **2019** and explained the current waiting list for support and the notes set out a management plan for AO.

In July a letter was written to AO advising of a support appointment on 19 August which AO subsequently attended. At this initial support session it was identified that there were issues around Mrs O's anxiety over AO and the management plan included Mrs O and AO being invited to a post diagnostic group (?) and AO being seen alone for one further support session to see if she required any further support.

AO had another session with the Psychologist in the December. Mr P, her Support Worker was also present. There were problems with the appointment in January 2020 (the Psychologist was on the sick and it was cancelled), and the appointment letters for the February and March appointment were not correctly addressed which led to AO not attending. The Psychologist wrote to AO on 19 March to say that she was leaving and that AO could contact Mr P to arrange a further appointment.

The next entry is on 18 May 2020 where Mr P refers to a telephone conversation that he had with Mrs O. In the entry he disputes that AO was allocated to him or was placed on the support waiting list. A letter (p.155) was subsequently sent to Mrs O under the Service Manager's name, apologising and noting that the "support and intervention from the IAS has not been at an acceptable level". She noted that the members of staff previously overseeing her case had now left the service and she was confident that all future contact with the IAS would result in improved support.

I note that in the statement that Mr P provided to the Ombudsman's office amongst the points that he makes is that he was allocated to AO for support in July 2019 (p. 90).

The Health Board, in a letter to Mrs O (p. 219) dated 24 August 2020, responded to the complaint that she had made to it.

I note that the IAS draft Operational Policy (2017) ("the 2017 Policy") refers to the fact that the assessment and support pathways would be informed by the New National Integrated Autism Service. At point 11.4 of the Policy it sets out possible limitations on the support that would be provided within the first 6 months. The 2017 Policy also made it clear that IAS would not duplicate existing services.

Incidentally, I note that Mrs O says that her daughter has been diagnosed with ADHD. This follows a recent referral from IAS. Again Mrs O feels that the possibility of AO having ADHD should have been considered pre May 2020.

Known guidance/strategies applicable in Wales

- Integrated Autism Service - Awtistiaeth Cymru | Autism Wales | National Autism Team

- Integrated Autism Service Supporting Guidance final draft (autismwales.org)

For background information

- Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: Interim report (autismwales.org)

Questions

Standard introduction to questions – this will be applicable in most cases:

I set out below questions relating to the complaints. For each question, please would you set out what happened, what should have happened, the impact of any difference between the two, and any remedy or recommendations to prevent recurrence or improve care for the future.

(1) NICE CG142 (2012) says that health and social care professionals should promote active participation in decisions about care and support self-management. Was this evident in the post-diagnostic sessions and later the support sessions provided to Mrs O and AO in the period up to 18 May 2020?

(2) Was it appropriate to carry out initial post diagnostic and support initial assessments in relation to Mrs O and her daughter?

(3) Please review the effectiveness and robustness of the post diagnostic care and support provided to Mrs O and AO up to May 2020 including the assessments and interventions against NICE CG142 (2012) and the Welsh Government Supporting Guidance?

(4) Given what you have seen do you consider the overall care and support that was provided up to May 2020 was appropriate?

(5) Post AO's autism diagnosis, on the evidence was record keeping in the clinical records up to May 2020 adequate?

(6) Please let me know if, in considering my questions, you identify any other relevant clinical matter from a patient safety in relation to the complaint that gives you cause for concern.

Thank you for your advice. If you need to discuss the case, please do not hesitate to contact me.

Swyddog Ymchwilio/Investigation Officer

Clinical Advice Form

Ombwdsmon Ombudsman
OMBWDSMON GWASANAETHAU CYHOEDDUS CYMRU
PUBLIC SERVICES OMBUDSMAN FOR WALES

TO BE COMPLETED BY CLINICAL ADVISER

Clinical Advice

Provision of Clinical Advice for Public Services Ombudsman for Wales
Background Information
Case Identifier (Case Reference): 20200XXXX
Clinical Adviser's Name and Qualifications: [Name] B.Sc.(Hons) Dip.Cog.Psy. Ph.D. D.Clin.Psy C.Pyschol A.F.BPsS
Relevance of qualifications and/or experience to clinical aspects of this case: [Relevant qulaifications provided]

Clinical Advice Form

Conflict of Interest (clarification of any links with Body or clinicians complained about): I know of no reason that would constitute a real, apparent or potential conflict of interest.
Confirmation that the Ombudsman's Clinical Standards have been applied in the provision of the advice I confirm that the Ombudsman's Clinical Standards have been applied in the provision of the advice.
Please confirm the chronology provided by the Caseworker in requesting this advice is correct and correctly identifies the relevant clinical events I confirm that the chronology provided by the Caseworker is correct and correctly identifies the relevant clinical events.

Any comments on Background and Chronology:

I would highlight that there is no response from the Board in the file following their meeting on the 21/1/21 with AO's parents. The Board had undertaken to look into the points raised by Mrs O in the meeting, in relation to missing information in the medical records. In addition, the Chronology set out by the Ombudsman suggests that AO was put on the "support" waiting list in December 18, when in fact, this occurred in response to a request by AO's mother in February 19. Please also refer to Q1 which provides further important background to understanding the case, particularly in relation to the two pathways within the IAS: the "post-diagnostic/assessment" and "support" pathways.

Documentation Reviewed:

HOME - IPA - Electronic Subfile. Referred to henceforth as "the File".

Questions and Responses:

1) NICE CG142 (2012) says that health and social care professionals should promote active participation in decisions about care and support self-management. Was this evident in the post-diagnostic sessions and later the support sessions provided to Mrs O and AO in the period up to 18 May 2020?

My Response to Q1:

In section 1.1.4 of the NICE guidelines (NICE, 2012) it states that:
"All health and social care professionals providing care and support for autistic adults should aim to foster the person's autonomy, promote active participation in decisions about care and support self-management".

It is first important for me to add the caveat that in the clinical notes there is very limited information about the precise content of the clinical sessions, other than some details reporting on AO's current situation. This has made it difficult to evaluate the exact nature of the care/support, and whether the NICE guidelines can be evidenced.

The appointments delivered in the timespan in question (prior to May 2020) pertain to two sequential component parts of the IAS's clinical pathway, namely the "post-diagnostic/assessment" pathway and the "support" pathway. It would appear that Dr Y fulfilled an important role in the first appointment on 30/08/18 in which the impact of the diagnosis of ASD was explored, and this lead to the equally important identification of some additional mental health needs which Dr Y was able to advise as to how AO could receive treatment. It seemed clear to Dr Y that she could not discharge AO, and so she planned to continue with appointments with AO within the "post-diagnostic/assessment" phase. This approach was clinically appropriate and was in keeping with the NICE guidelines, as Dr Y was at the very beginning of the process of "fostering autonomy, promoting participation and supporting self-management", and had for example encouraged AO to speak to her GP about what counselling options were available for her.

It appears from the notes that Dr Y had then offered follow-up to AO after the appointment on 30/08/18, however the agreement had been for AO's mother to contact the service when she was clearer on how the appointments would fit in to AO's College schedule. When AO was accepted for Mental Health Service treatment by her Primary Care team (LPMHSS), Dr Y closed AO's initial "post-diagnostic/assessment" phase and sensibly offered to consult with the LPMHSS (as described in the notes on page 121 in the File, and in the letter from Dr Y on Page 173 in the File). In addition, Dr Y also offered to move AO to the second "support" pathway of IAS and requested AO to opt in to this (the implication being

perhaps that the family did not want this at the time). This again broadly accedes to NICE guidelines, as it fosters autonomy in making decisions about AO's care.
In terms of AO commencing the second "support" pathway in the IAS, it is unclear from the notes exactly how this was initiated as there was no record of a specific request from AO's mother other than a letter from the IAS on 18.02.19 (on page 172 in the File) thanking AO for a request for support. Subsequently, there is a telephone call between Dr Y and AO's mother on 22/02/19 (Page 122 in the File). Dr Y discussed the waiting list for support and the "Request for support" forms were received back from AO in the IAS on the 27/02/19 (Page 167 in the File), and as per the letter from IAS dated 18/02/19 (on Page 172 in the File), AO was officially moved to the waiting list for support on this date.

The aforementioned letter confirming that AO had been placed on the "support" pathway stated that there would be "a short wait for support", but a first appointment only became available on 18/08/19 almost 6 months later (note that this letter was sent on the 22/07/19 and **not as recorded in the Board's chronology in the File**: "22/02/2019 Letter Appointment for 19/08/2019"). It would appear that this wait of six months to initiate the "support" pathway from the time of request was recognised as too lengthy by the Board and is reflected in their Audit as an area requiring immediate and urgent improvement (Page 108 in the File: Audit Reference IAS3). As such, this would not be compatible with the NICE guidelines due to the lack of intervention. To compound this, following the initial first two "support" appointments, where an appropriate clinical plan was formulated, the care then fell short of the NICE guidelines again as AO did not receive the input due to the appointment letters being sent to the family with the wrong Postcode, and apparent miscommunication within the team about who Dr Y was passing AO's case over to when she left the IAS at the end of March 2020 (Dr Y's departure is detailed in her letter on page 160 of the File). It was only due to AO's mother contacting the service that care was subsequently resumed for AO after May 2020.

2) Was it appropriate to carry out initial post diagnostic and support initial assessments in relation to Mrs O and her daughter?

My Response to Q2:

Yes, this will be implicit parts of both pathways, and it is common practice within Mental Health Care Services that assessments are always required to assess need before providing any form of intervention, so as to accurately inform what is delivered.

3) Please review the effectiveness and robustness of the post diagnostic care and support provided to Mrs O and AO up to May 2020 including the assessments and interventions against NICE CG142 (2012) and the Welsh Government Supporting Guidance?

My Response to Q3:

See response to Q1. In addition, Section 1.6 of the Welsh Government Supporting Guidance (page 25) specifies that post-diagnostic support should include "information about what autism is and what it might mean for the individual, family or carer, now and in the future". However, as referenced above it is not clear from the records what was discussed with AO's family in the "post-diagnostic/assessment" phase, and this may have been subsumed under Dr Y's general note (on page 121 of the File): "Discussed outcome of Autism diagnosis & recommendations", but there is no further detail to evaluate what areas were covered.

4) Given what you have seen do you consider the overall care and support that was provided up to May 2020 was appropriate?"

My Response to Q4:

See my response to Q1 and Q3. The overall care and support were generally more appropriate in the "post-diagnostic/assessment" pathway but not in the "support" pathway. However, note that due to the lack of detail in the notes it is difficult to evaluate the nature of the input during the "post-diagnostic/assessment" phase. It is possible that further detail would have been recorded if AO would have had further appointments during this phase.

5) Post AO's autism diagnosis, on the evidence was record keeping in the clinical records up to May 2020 adequate?

My Response to Q5:

There seems to be a suggestion from AO's mother that some telephone calls have not been documented in the notes, but this is hard to evaluate when looking at the Records alone, and I note that the Board's response to the meeting on 21/1/21 which should address was not in the documentation made available to me. However, what is more readily appropriate to comment on is the content recorded in the clinical entries pertaining to the appointments. There is a general paucity of information about the specifics of the discussions held and the content of the sessions delivered. For example, in relation to the appointment on 30/08/18 where the "post-diagnostic" session is held, there is no detail about how the content of the ASD Diagnostic report (Page 185 of the File) was discussed e.g., how were the specific recommendations discussed and thought through. It

might be that there is a proforma with further details, but this could not be found in the file. This lack of content has made it more difficult to evaluate the exact nature of the care delivered within IAS. Also see my response to Q4.

6) Please let me know if, in considering my questions, you identify any other relevant clinical matter from a patient safety in relation to the complaint that gives you cause for concern.

My Response to Q6:

It is concerning that Dr Y describes IAS (in point number 7, on Page 93 of the File) as having been a service where staff members were "being ignored" by other members of the team. This creates clinical risks for patients as information will not be effectively communicated, and this environment will affect the delivery of a service to patients (Rosen et al, 2018). Although this is clearly the retrospective report of someone who has left the service, who may have her own personal "axe to grind", there is certainly circumstantial evidence for this suggestion as Mr P claimed not to have been aware that AO was on the support waiting list, and allocated to him, despite this being recorded in Dr Y's letter dated 09.03.20 (page 160 in the File).

In addition, the offer of liaising with AO's LPMHSS was not revisited with the family following the initial suggestion by Dr Y, which would have been important to ensure that all services gained an understanding of AO's clinical picture and were operating in a safe and compatible way with their respective treatment plans.

Recommendations:

It is pleasing that AO is now receiving better care from IAS (post May 2020) and so there has apparently been a change in the way that AO's care is now being delivered. I am unclear however whether changes in the documentation and recording have been addressed by the Board as part of this, in line with my comments above. For example, in order to evidence that the "post-diagnostic/assessment" package of care is comprehensive and is in line with guidance it would be helpful for IAS to have a proforma to follow in this part of the pathway that ensures that clinicians include the key components of this in their care, as per my response to Q3. This proforma could perhaps reference all of the bullet points on page 25 in Section 1.6 of the Welsh Government Supporting Guidance) and prompt to record the pertinent plans and themes of discussions. In addition, the Board's response to the meeting on 21/1/21 with AO's parents needs to be identified in the file, and any additional content relating to record keeping needs to be factored into this complaint.

Conclusions:

In the time-span under my review (i.e. until May 2020), the "post-diagnostic/assessment" pathway was much better delivered to AO than the "support" pathway, as the "support" pathway fell short in terms of AO accessing input and care. There were also deficiencies around record keeping in both phases.

Clinical Standards – List of Guidance and Policies Referenced (please provide link to relevant/current document)

1. Welsh Government Consultation Document Code of Practice on the Delivery of Autism Services Supporting Guidance Document

2. NICE Guidelines (2012) CG142. Autism spectrum disorder in adults: diagnosis and management

3. Rosen et al (2018). Teamwork in Healthcare: Key Discoveries Enabling Safer, High-Quality Care. Am Psychol. 2018 May-Jun; 73(4): 433–450.

Name & Signature:

Date: 03.01.22