



Llywodraeth Cymru
Welsh Government

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Welsh Government
Consultation – summary of response

Transition and Handover from Children to Adults' Services

February 2022

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

Overview

Welsh Government guidance on the management, handover and accountability of healthcare services for children and young people during their transition from children's to adults' services

Action Required

This document is for information only.

Further information and related documents

Large print, Braille and alternative language versions of this document are available on request.

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Additional copies

This summary of response and copies of all the consultation documentation are published in electronic form only and can be accessed on the Welsh Government's website.

Link to the consultation documentation: [hyperlink](#)

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Introduction

The provision of appropriate healthcare for children and young people between the ages of 16 and 25, and handover of care and accountability from children's to adults' services has been highlighted as a key priority for improvement. This was flagged by the National Assembly for Wales' Children, Young People and Education Committee, in its 2014¹ report on Child and Adolescent Mental Health, and by the Children's Commissioner for Wales in recent years², calling for good quality 'transitional care' for this group of the population, from all health services.

About the consultation

There was a need to ensure that transition and handover between paediatric and adults' services was as seamless as possible and that children and young people have a say in the way they move between services.

In 2019, officials established a task and finish group which included key stakeholders from across health boards, social services and third sector organisations to produce Welsh Government guidance detailing the provision of appropriate handover of health care from paediatric to adults' services.

The focus of the guidance is on what health services need to do to ensure that a well-structured, effective process is in place to meet the integrated healthcare needs of children, young people and young adults, promote quality and safety, access, autonomy and efficient care for better health outcomes.

Officials have also developed a draft pathway to help children and young people navigate through the healthcare system.

Officials launched a consultation on the draft guidance on 27 January 2020. The consultation was originally intended to last for 12 weeks, but was extended due to the inability of many health bodies to respond in the usual timescales due to the Coronavirus pandemic.

About the consultation responses

We received **86** responses in total to our consultation from Health Boards, Royal colleges and clinicians from across Health and Social Care and a number of Third sector organisations including Charities.

We received **45** responses via our electronic consultation portal. Summary of the results via the portal:

- 85.37% of responders felt that the guidance was clear as to the management of Transition and Handover within the Health Board.
- 100% of responders agreed with the principles that underpinned the delivery of individualised care to plan and deliver the move from children to adults' services.
- 87.80% of responders felt that the guidance was clear about the young person's journey on the Transition and Handover process from start through to completion.

¹ <https://senedd.wales/committees/children-young-people-and-education-committee/>

² <https://www.childcomwales.org.uk/wp-content/uploads/2019/10/Annual-Report-2018-19.pdf>

- 78.05% of responders felt that the guidance was clear about the process for a young person entering the healthcare system for the first time at 16 or 17.

Key themes that emerged out of the consultation responses – Summary only

Please note that this is not an exhaustive list of all responses received. However, all responses have been carefully considered.

i) Mental Capacity

- There was a need to include further detail in relation to issues around consent and mental capacity.
- Greater clarity was needed to outline whether mental health services was included in the scope of the Guidance.

ii) Advocacy

- There was a need to highlight in detail the importance for children and young people to have access to appropriate information on advocacy services before the transition journey started.
- Responders outlined that there was a varied picture of advocacy services across Wales and concerns around the lack of independent advocates for young people in certain areas of practice in particular.
- Consideration for the named worker to become a source of easily accessible information around healthcare advocacy and for wider support.

iii) Transition and Handover Lead

- Greater clarity was needed around the role of the Transition and Handover lead, if a single post across the Health Boards and if the lead would sit within children or adults' services.

iv) Young Person entering the healthcare system for the first time at 16 or 17

- Responders outlined that without more emphasis on the specific needs of 16-25 year olds, and stronger and clearer guidance for paediatric and adults' services to work together throughout the document, it would be difficult for services to create a more joined up approach to their services.
- There should be guidance for those age 16-25 who were entering the healthcare system for the first time which would mean that support to these young adults could be tailored to their needs, and their care was person-centred rather than dictated by an arbitrary age range.
- Some concerns around the additional demand on capacity.
- There were concern around the competency of some health professionals working with patients beyond the age of 16.
- Concerns around some children on waiting lists for certain services that may be disadvantaged if moving from children to adults' services whilst on the waiting list.

v) Named worker

- Consideration was needed to appoint a named worker for every child or young person managing the transition from child to adults' services.
- Consideration as to whether there was a specific need for further support for children and young people who were looked after in relation to continuity,

ongoing support, out of area arrangements, support around self-management and communication post leaving care when those young people are most at risk of being lost and experiencing a lack of continuity in care and support.

- Consideration should be given to wider health and social care services other than statutory health services and local authorities, e.g. registered social care workers, third sector and wider agencies or services. They may have an existed trusted relationship with that individual and may thereby be best placed to act as a named worker.
- Further guidelines on how the named worker is identified. If this would be a new role within the health board or if this responsibility will become part of an existing clinicians role.

vi) Transition and Handover Plan

- There was a need to consider how different plans would fit together as parents of children with complex needs often feel overloaded by the number of different plans i.e. Education and Social Care.
- More detail was needed in the document about how the plan will be used and communicated effectively with young people, and all professionals involved in their care.
- Clarity as to whether the plan could be individualized.
- There was a need to include a section to outline a young person's communication needs.
- The Plan must document the ongoing clinical accountabilities for care by respective services, the timing and nature of clinical handover and coordination (e.g. clinical lead, need for joint clinics, referral for additional services, timing and handover, etc.). Consideration needs to be given to the detail as to how joint clinics might work and where they might occur. There may need to be extra resource provision to support these.

vii) Suitable Environments

- Further consideration around the environments that the need for them to be psycho-socially appropriate for children and young people, recognising that adult clinical environments, particularly acute settings, can be scary and intimidating for children and young people.
- The guidance did not elaborate on what an 'age appropriate environment' was and how it would be implemented by Health Boards.
- There were safeguarding concerns to consider. E.g. should (young) adult men or women of 16 or 17 years be cared for on the same wards or the same clinical area as much younger children?

viii) Primary care/GPs

- Respondents outlined that the guidance needed to proactively engage GPs as often they have not been involved in the care of young people with complex needs.
- Many outlined the importance of the role of the GP and structures needed to be in place to support this engagement and identify patients early enough for planning to take place.
- Respondents outlined that ideally, the GP would be invited to the transition clinic and would attend.

ix) Monitoring and Reporting

- Respondents outlined that it would be important to include more detail around when reviews or evaluation referred to individual cases and when it referred to the whole system.
- Clearer and more consistent reporting of performance was needed to better facilitate such scrutiny by the Health Boards themselves and by those who use and monitor the NHS.

x) Welsh languages

- It is important that stakeholders are able to conduct proceedings in the Welsh language if they so wish and the option should be easily available.
- All documentation and literature regarding the transition process should be bilingual – Welsh and English.
- If the language of choice of a family is Welsh there should be proactive attempts made to either have Welsh speaking professionals involved or translation facilities available.

xi) Access to services

- This was a concern particularly for young people who had difficulty accessing services because of disability or disadvantage (including digital poverty), and for young people who had not accessed services previously and who would lack support to navigate complex healthcare systems.
- In addition to access to services, it would be useful if this also covered identification of those groups of children who may face more barriers to self-management and adhering to their treatment.
- Some children and young people may be disadvantaged if, because of long waiting lists, they had not been able to access a service before moving on to adults' services.
- For the majority of young people they would be able to access adult specialist services more locally than Paediatric specialist services.
- Some young people may be disadvantaged when trying to access health services for the first time at age 16 or 17 if that service had an existing waiting list.
- There was a variation in terms of service availability across the specialties, with some services being less well developed in adult practice when compared with Paediatric practice

xii) Cross Border / Rural

- There was a need to consider children and young people who had ongoing treatment from hospitals in England
- Powys Teaching Health Board commissioned children's specialist care outside Powys with a large proportion of the care being provided in England. It may be difficult to monitor children's transition in these instances.
- Some children and young people may not always be treated in Wales due to the lack of specialists and services. This exposed the problem of cross-nations transition.

xiii) Training

- Respondents outlined that paediatric specialists, on the whole, were trained and experienced in looking after babies and younger children. They are were

not used to looking after young adults. They are not necessarily competent to do so and may not consider other, different, problems that adults can acquire.

- There was a need for a real drive to ensure that the “receiving services” were trained and equipped to actually meet the needs of a very vulnerable group, i.e. emerging adults under the age of 30. The current document addressed the issue of preparation from the paediatric side but did not adequately address the accommodation of this group in adults’ services.

xiv) Technology/IT

- It was noted that IT systems were not at the point of shared systems; the transfer of information was not smooth. There was an urgent need for a shared platform that all agencies could access.

xv) Palliative Care

- Many children and young people with complex palliative care needs would have a multitude of care plans including Advanced Care Plans so this needed to be taken into consideration.
- There may be a need to review plans several times if the young person’s condition was unstable or deteriorating. They may require input from palliative care.

xvi) CAMHS/AMHS/Mental Health Services

- There could be greater clarity, from the outset, as to whether the document referred to physical or mental health conditions, or both.
- The guidance did not address the core issues of transitions in mental health.
- There was a need to be more definitive, Mental Health and Medical services have different age groups that cut off at 16 or 18.
- The differences in the way mental and physical health services operate meant that an overarching guidance might not be well suited for mental health services and might not help to reach the best outcomes for all children and young people.

Next steps

Welsh Government has considered all responses to the consultation and has made necessary changes within the guidance.

Table of Responders

Reference	Mailbox/Online	Organisation	Anonymous
1	M	Social Care Wales	No
2	M	National Deaf Children's Society Cymru	No
3	M	Children's Legal Centre Wales	No
4	M	Emotional Wellbeing Service	No
5	M	Specialist Childrens' Services – Ynys Mon	No
6	M	Newport City Council	No
7	M	BCUHB East	No
8	M	Ashraf Elhenawy – CTM	No
9	M	XXXX	Yes
10	M	Welsh Women's Aid	No
11	M	North Wales Community Health Council	No
12	M	XXXX	Yes
13	M	Royal College of Physicians Cymru	No
14	M	Bangor University's Disability Service and Mental Health Team	No
15	M	Royal College of GPs	No
16	M	Ty Hafan	No
17	M	XXXX	Yes
18	M	CCFW	No
19	M	Children and Young People's Diabetic Network	No
20	M	The Down's Syndrome Association	No
21	M	Ceredigion County Council	No
22	M	Royal College of Occupational Therapists	No
23	M	Occupational Therapy Learning Disability Service	No
24	M	RCN	No
25	M	Hywel Dda UHB	No
26	M	Torfaen County Borough Council	No
27	M	Mind Cymru	No
28	M	Coeliac UK	No
29	M	Community Health Council in Wales	No

Reference	Mailbox/Online	Organisation	Anonymous
30	M	All Wales Paediatric Occupational Therapy Network	No
31	M	XXXX	Yes
32	M	National Rheumatoid Arthritis Society	No
33	M	Royal College of Speech and Language Therapists	No
34	M	Diabetes UK Cymru	No
35	M	British Psychological Society	No
36	M	RCPCH	No
37	M	Bay Youth	No
38	M	XXXX	Yes
39	M	Royal College of Psychiatrists Wales	No
40	M	WHSSC	No
41	O	XXXX	Yes
42	O	XXXX	Yes
43	O	Romana Murray	No
44	O	XXXX	Yes
45	O	XXXX	Yes
46	O	No Details	No
47	O	XXXX	Yes
48	O	Nicola Butland	No
49	O	Hafal	No
50	O	Ilona	No
51	O	XXXX	Yes
52	O	Katie Malbon – Imperial College Healthcare NHS Trust	No
53	O	XXXX	Yes
54	O	XXXX	Yes
55	O	XXXX	Yes
56	O	XXXX	Yes
57	O	XXXX	Yes
58	O	XXXX	Yes
59	O	XXXX	Yes
60	O	XXXX	Yes
61	O	XXXX	Yes
62	O	XXXX	Yes
63	O	Rhys Meredith – SBUHB	No
64	O	SNAP Cymru	No
65	O	No Details	No
66	O	Elizabeth Scott – Black Country Healthcare Foundation Trust	No
67	O	Charlotte Scott – HDdUHB	No

Reference	Mailbox/Online	Organisation	Anonymous
68	O	XXXX	Yes
69	O	XXXX	Yes
70	O	XXXX	Yes
71	O	XXXX	Yes
72	O	XXXX	Yes
73	O	XXXX	Yes
74	O	Cari Watts – HIW	No
75	O	XXXX	Yes
76	O	XXXX	Yes
77	O	XXXX	Yes
78	O	Angela Wing – BCUHB	No
79	O	XXXX	Yes
80	O	No Details	No
81	O	Vanessa Hammond/Rebecca Saltmarsh – on behalf of psychologists SBUHB	No
82	O	XXXX	Yes
83	O	XXXX	Yes
84	O	XXXX	Yes
85	O	Dan Steer – Together for Short Lives	No
86	M	RNIB	No