

Safe Harbour: the role of lead professionals at the time of transitioning between child and adult services for those with life-limiting conditions

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Abbr. abstract: The proposed Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill requires each disabled child and young person to have a plan in place as they move into adulthood. The Young Adult (YA) Service at The Prince and Princess of Wales Hospice has a role to play in the establishment of such plans as they often fulfil the role of lead professionals in the YA's care, focusing on "Getting it Right for Every Child" (GIRFEC).

Related publications:

- Getting it right for every child: understanding wellbeing leaflet. The Scottish Government 2018
- <https://www.parliament.scot/-/media/files/legislation/bills/s6-bills/disabled-children-and-young-people-transitions-to-adulthood-scotland-bill/introduced/bill-as-introduced.pdf>



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In the beginning...

- Recognising the value of the principles of GIRFEC and SHANARRI (safe, healthy, active, nurtured, achieving, responsible, respected and included) wellbeing indicators, they were incorporated into clinical assessments at PPWH by re-designing several of clinical assessment windows and review topics.
- This was done in consultation with the YA MDT: the aim - to promote independent living and quality of life for as long as possible in YAs with life-limiting conditions.
- Identification of areas of unmet need and the lack of co-ordinated MDT care across the YA's specialist teams meant the YA Service was often working in the best interests of the YAs to address their unmet needs.

Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill

[AS INTRODUCED]

- The proposed Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill introduced to Parliament mentions Health Boards having a duty in complying with the proposed National Transition Strategy. This inclusion in the Bill encouraged the YA service to look at their role as lead professionals in transition planning to ensure the wellbeing of YAs



Unmet Needs

The SHANARRI wellbeing indicators (safe, healthy, active, nurtured, achieving, respected, responsible and included) influence the coordination of care and wellbeing for the YAs attending the Service, allowing for the identification of areas where needs are unmet and further attention is required. The Service plays a lead role in supporting the YAs adults to ensure their needs are met.

For example, the YA Service has:

- Co-ordinated GP review and admission for an acutely unwell YA during the height of the pandemic
- Helped gain access to an orphan medication which could potentially improve a YA's overall wellbeing
- Supported a YA to move into their own accommodation with a suitable (and extensive) care package
- Supported a YA to challenge their right to eat; they felt they were being denied a fundamental human right
- Identified that for YAs appropriate environment controls are essential, driving the change needed at PPWH
- Ensured improved and timely MDT communication to make safe an unsustainable situation at home for a YA
- Championed access to mental health services for YAs who cannot access appropriate services.



Meeting the needs of the YA

Palliative care teams are uniquely placed to **play a role as lead professional** in the establishment and review of transition plans from child to adult services for those with life-limiting conditions.

By considering the below questions we can ensure that unmet needs are identified and addressed, with the overall outcome of improving wellbeing:

- **What is getting in the way of this individual's wellbeing?**
- Do you have all the information you need to help this individual?
- What can you do now to help this individual?
- What can your place of work do to help this individual moving forward?
- What additional help, if any, may be needed from others? e.g. health, social, and third sector partners

Ultimately, **without health, a child cannot transition from child to adult services** for it underpins overall wellbeing and quality of life. Without a plan in place for transition, the future safety of the young person – and their families - is put in question.

Be the lead professional these YAs need you to be.

