

Hear Their Voices: The Importance of a Young Adult Clinic

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Abbreviated abstract: Transitioning from paediatric services to adult services is a time of great change. It is known that adults with certain life-limiting conditions receive less comprehensive, co-ordinated care compared with children¹. As a result, adults often feel like their voices are not heard. Our Young Adult (YA) Clinic provides a safe and supportive environment in which the YAs can share their stories, feel in control of their wellbeing and enjoy an overall improved quality of life.

Related publications:

¹Bushby K, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management. *Lancet Neurol.* 2010; 9: p. 77-93.

² Scottish Government. Getting It Right For Every Child. Available from: <https://www.gov.scot/policies/girfec/>



The Young Adults

16 YAs currently attend the monthly clinic: 15 live with Duchenne Muscular Dystrophy, 3 with complex neuro-disabilities and 1 with Spinal Muscular Atrophy.

All are living with complex physical, psychological, and social issues (Figures 1 &2)

94% male

Age range: 17-42 yrs with a median age: 25 yrs

Figure 1: Prevalence of Presenting Symptoms

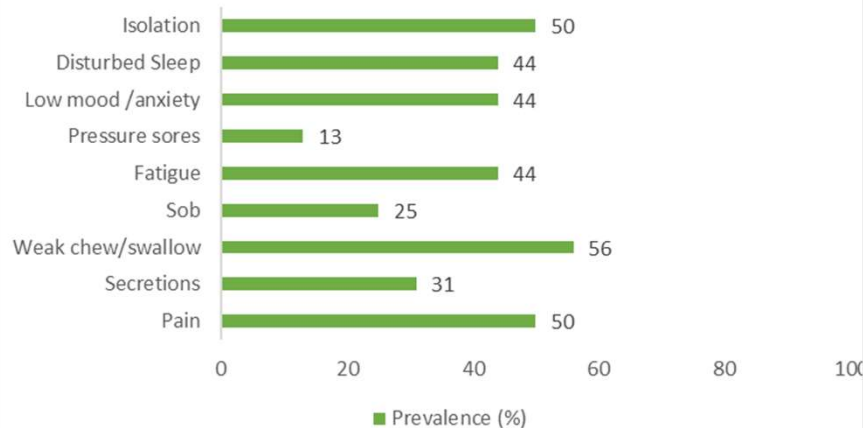
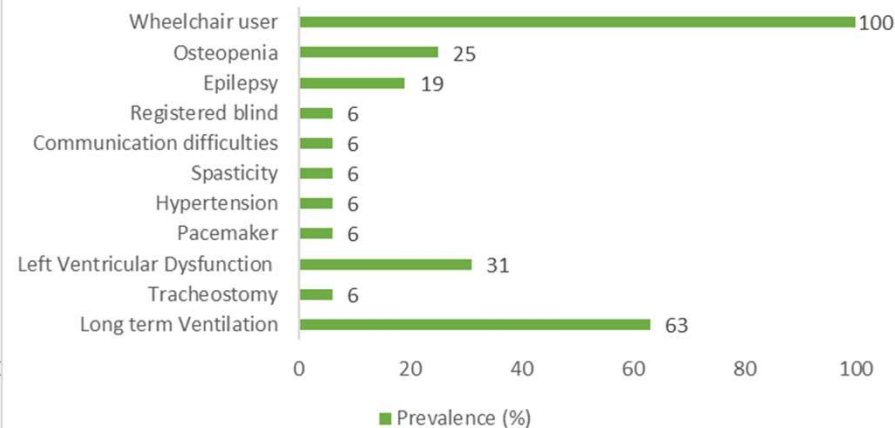


Figure 2: Prevalence of Co-Morbidities



Voices Matter

- Young Adults (YA) currently attending PPWH are living longer with complex conditions that currently have no cure. A dichotomy exists: with advancing age comes the desire for autonomy and control over their own lives.
- How do we encourage them to share their stories, ensuring that the YA feels listened to and that their wishes have been heard and understood?
- We ask them to consider the SHANARRI wellbeing indicators² in terms of “What makes a good day **good**?” (Figure 3).
- From there a YA led therapeutic relationship begins...

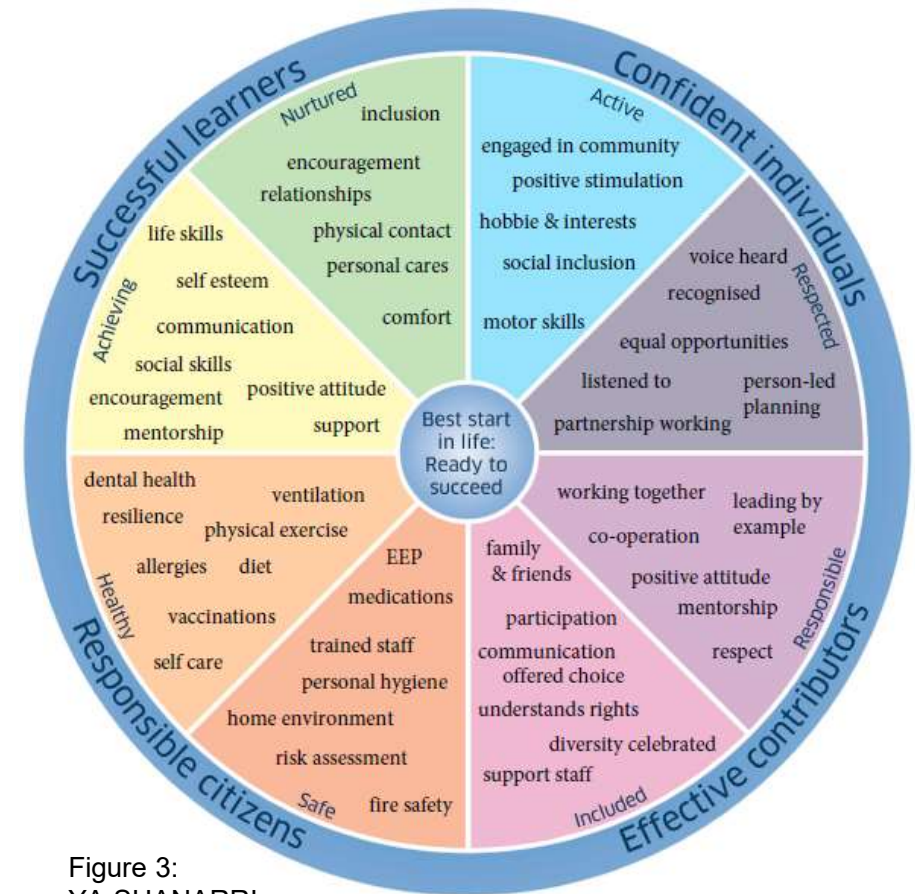
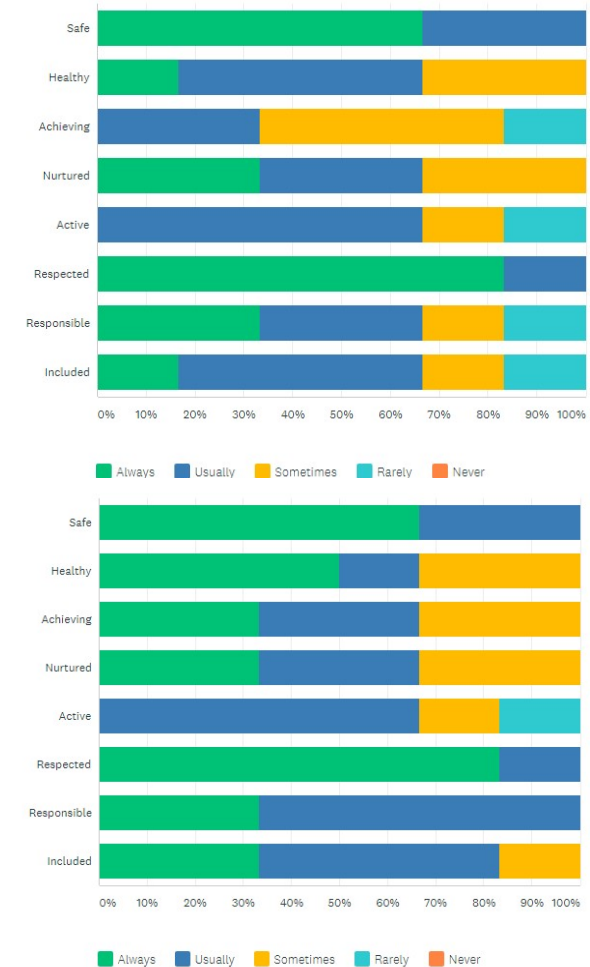


Figure 3:
YA SHANARRI

Voices Shared

- Using the SHANARRI wellbeing indicators to evaluate the clinic we asked “If you can think back to a time before you had input from the YA Clinic, how would you rate how you felt in the following areas?” (Figure 4)
- Followed by, “If you can think about now, having had input from the YA Clinic, how would you rate how you feel in the following areas?” (Figure 5)
- The results show that the YAs feel they are **achieving** more, are more **responsible** and are being **included**.
- One individual, when asked “What entices you to participate in the YA Clinic?” replied, “**It makes my life better...**”
- What have we learnt? That the **informal setting** of the clinic and **the holistic approach to care**, along with the use of **pre-clinic key documents**, allow the young person’s voice to be truly heard. Members of staff are found to be **approachable, knowledgeable** and **contactable**. The development of a **YA-centred individual-professional relationship** is essential and provides the foundation to ongoing care..



Figures 4 (top) & 5 (bottom)