HQIP
Healthcare Quality
Improvement Partnership

NCEPOD

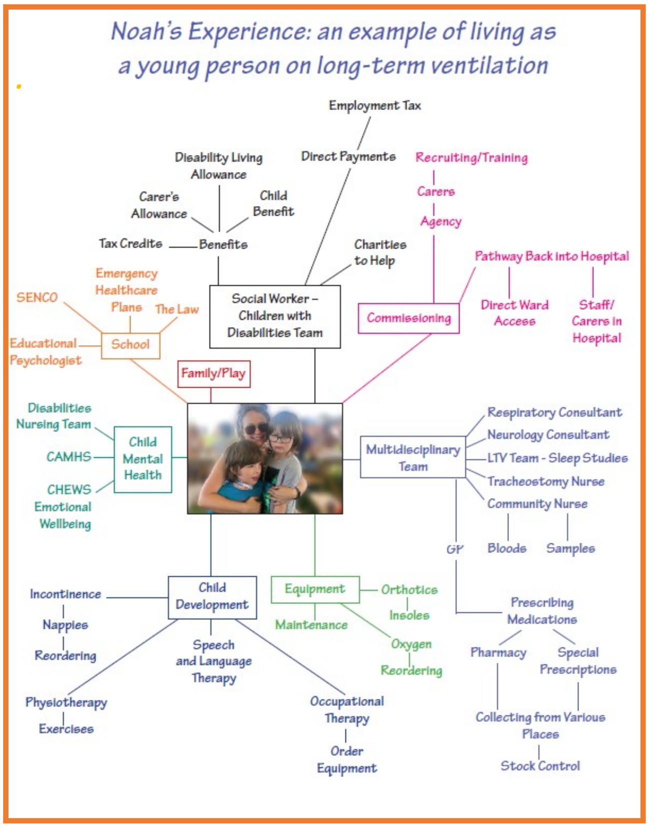
CHILD HEALTH CLINICAL OUTCOME REVIEW PROGRAMME

INVOLVING YOUNG PEOPLE AND PARENT CARERS

Examples of patient input throughout a study and the impact of lockdown

LONG-TERM VENTILATION

Long-term ventilation—’Balancing the Pressures’ was published in February 2020. This study looked at the quality of care received by young people receiving long-term ventilation in hospital or the community.



Noah’s Experience: an example of living as a young person on long-term ventilation

We used Noah’s story on the inside cover to set the scene of why the care of this patient group is so complex

> *“Local hospital is lacking in knowledge and facilities to cope with a LTV child that is ill. GP also relies on lead children’s hospital or us as parents for guidance”*
>
> *Service user/parent carer*

> *“Local hospital aren’t trained in non-invasive bilevel ventilation so either dislike admitting her, or will admit on the proviso that we do not leave her side throughout the whole time she’s using her ventilator”*
>
> *Service user/parent carer*

Seventy respondents provided free-text comments that related to areas of LTV care that worked well, and 59 respondents provided free-text comments about things that could be improved (Table 2.2).

Table 2.2 Most common free-text comments made by respondents to the service user/parent carer survey

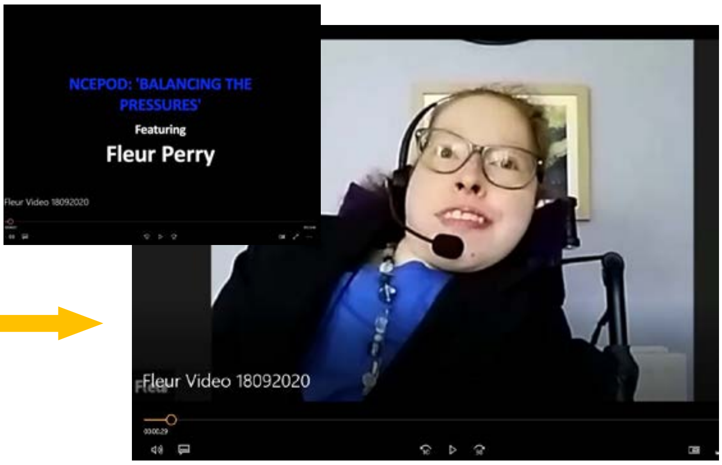
Aspects of LTV services that worked well	Aspects of LTV services that could be improved
27 responses referred to a positive experience of access to the specialist LTV team for support (e.g. prompt outpatient reviews, telephone access and email contact when needed)	14 responses raised issues about the competence or training of staff providing care in the community
23 responses were in relation to skilled or caring healthcare professionals	10 responses were with in relation to access to advice or follow-up arrangements
11 responses were about the convenience of home assessments for sleep studies	6 responses commented that access to sleep studies could be improved
11 responses were about access to equipment	5 responses were that local hospitals did not have the necessary knowledge of LTV to provide effective care
7 responses were with regard to training received	

Answers may be multiple; n=70 respondents commenting on where services worked well and n=59 respondents commenting on what could be improved
Service user/parent carer survey

To support the clinical findings we used data from patient and parent carer surveys and focus groups to extract powerful quotes that were used throughout the report to bring the data to life.

To help share the messages from the report and the views of a young person receiving LTV, Fleur Perry agreed to do a video interview for us. This was scheduled to be filmed in March at her house in Wiltshire. However, due to COVID-19 we did this remotely, which was a surprisingly positive experience for everyone.

Pre-COVID we would have felt that this was the least professional way to do a video, but because it became the only way, it opened up an opportunity. Scheduling and recording were more efficient, less equipment was needed and most importantly Fleur did not have us turning up on her doorstep!



INVOLVING YOUNG PEOPLE AND PARENT CARERS

Examples of patient input throughout a study and the impact of lockdown

TRANSITION

This study is just starting and will look at the care provided during the transition from child to adult healthcare services. Lockdown provided an opportunity to focus on gathering the views and experiences (good and bad) of young people and parent carers at a much earlier stage than usual in the development of a study.

An online survey was made available, and is still running. Data are being collected and themes analysed to share with the study advisory group to aid the design of the study and ensure the voice of the young person is at the centre of it, this is a method that will now be adopted for future studies.

> *"Using the three positive elements [planning, communication and documentation] we built a productive environment where all parties became a team to drive the transition process forward. However, barriers were encountered because many services do not engage well in a team environment as adult services is more fragmented and creates a larger logistical conundrum."*

> *"My adult and paediatric healthcare teams joined for a combined clinic to put me at ease and introduce me to the adult team who'll be looking after me in the future."*

> *"Transitioning from child services into adult services is like falling off a cliff. You transition from a proactive service into a purely reactive service. Often badly organised and or inexperienced in very complex health issues. No one health professional takes on the mantra of your paediatrician. You are back to each professional looking at their one special part of your young person.*
>
> *Nightmare if as a mum or dad you cannot pull all of the parts of the team together yourself. Many services just disappear. Frustrating for parent/carers but often life limiting for our young people. To quote a friend as my son approached adult services time, I hope xxxx dies while still in children's services then at least there will be support available. Upsetting but so true."*

In addition to the survey, four online focus groups have taken place with young people and parent carers. As with the video of Fleur (overleaf), lockdown removed any opportunity for organising local face-to-face focus groups around the country, as planned, but in fact this made it easier and the groups more accessible for participants. Parent carers did not have to organise childcare at all, or for as long they would have done if they needed to travel, and we were in the privileged position of seeing into their homes and to meet some of the young people they were telling us about.

Social media, Facebook and Twitter, proved to be the best way to find young people willing to get involved and we will continue to use this to promote participation opportunities as the study progresses.

Not only does the data collected from young people and parent carers benefit the programme and the final report, but it benefits us as providers. We see lots of data and read many sets of case notes, and it is too easy to become hardened to the stories that we read, or see them as 'data'. Hearing first-hand from participants their experiences and often the desperation and emotion in their responses, has a huge effect on the team involved and pushes us to strive just that bit harder to produce a report that drives change for future patients.