



Pathways

Transferring young people with complex needs from a
Consultant Paediatrician to a Consultant Adult Physician

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Introduction

“Why is it socially unacceptable for young adults who have diabetes, previous or ongoing oncology or cardiac issues not to have a seamless and resourced adult care, while for [children with complex neurodisability] it is still acceptable that they do not? Society needs to change its attitude or maybe it requires legislative action?”¹

Williams A et al. Enchanted Voice.

Archives of Disease in Childhood. 2018;0:1-2

The number of young adults with complex medical needs and/or life-limiting conditions living into adulthood is increasing internationally as a result of early detection, advances in medical treatment strategies and improved health. These young adults, with their families, typically face chronic, disabling, progressive diseases, which require a range of specialist services to manage their complex needs. Yet the literature shows that their needs are not being met during their transition from children’s to adult services²⁻⁵ and the needs of those with intellectual disabilities are not being met over the course of their lifetimes⁶.

Though the evidence to support exactly which transition program interventions improve outcomes remains sparse, there is a wealth of qualitative data supporting an early start to the transition process, an integrated approach and good communication between children’s and adult services, adequate parental involvement and developmentally appropriate healthcare.

A good transition program can lead to higher satisfaction, improved perceived and actual health status, greater independence/self- management and better provision for disease specific educational needs⁷. For a few specific conditions such as type 1 diabetes and cystic fibrosis, there has been an improvement in the last 5 years in health outcomes post transition through the application of a structured multidisciplinary transition program⁸ but equivalent programs for young people with disabilities are not well established¹.

Young people with complex medical needs currently transfer from a community paediatric team coordinating the multidisciplinary involvement in their care, to adult services where multiple specialists manage specific diagnoses and more holistic support is via their GP. The model changes from being proactive to reactive, with fragmented episodes of care (figure 1).

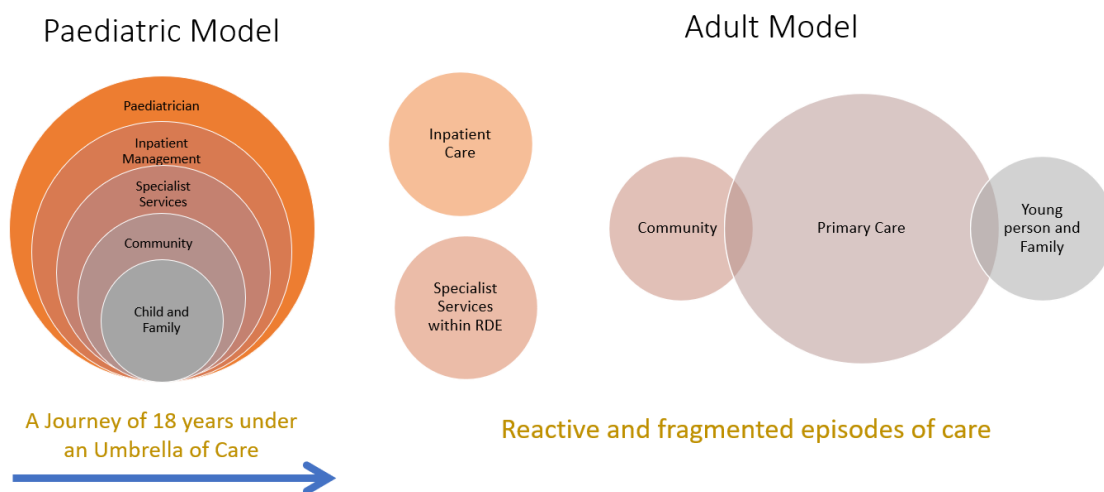


Figure 1. Paediatric model of care vs adult model of care for young people with complex medical needs

The National Institute for Health and Care Excellence (NICE) recommend that teams conduct a ‘gap analysis’ to understand the difference between the amount and type of services needed and the amount available, paying particular attention to young people with

neurodevelopmental disorders, cerebral palsy, challenging behaviours and those who are being supported by palliative care⁹.

In this article, we describe how we identified the need to improve the experiences of disabled young adults and those that care for them in accessing secondary healthcare and how through co-production with stakeholders, we developed our services in line with NICE guidance⁹ and recommendations from the NCEPOD Each and Every Need Report¹⁰.

Methods

The pilot project took place at the Royal Devon and Exeter Hospital NHS Foundation Trust from January 2018 to March 2020.

Participants and recruitment

A consecutive sample of adolescents and young adults was identified by clinicians within community child health and transition who met eligibility criteria. Included were young people aged 16-21 years with diagnoses affecting 2 or more biological systems, one of which must be a neurodevelopmental disorder.

Quality improvement methodology was applied to setting up a pilot clinic using Plan, Do, Study, Act (PDSA) cycles (figure 2).

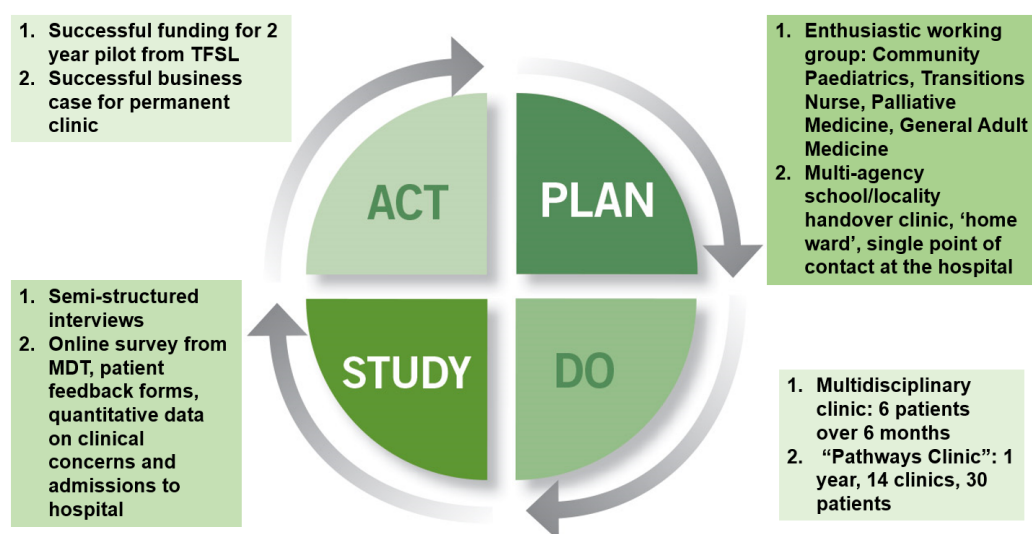


Figure 2. Outline of Pathways Clinic PDSA cycles. TFSL – Together for Short Lives.

An initial focus group was held with parents of young adults with complex needs at a local special school which confirmed that local voices were echoing national concerns about transition, and provided impetus to starting a pilot clinic. Once the pilot was underway, parent carers were approached and gave informed consent to be part of the service evaluation by undergoing semi-structured interviews. Parent carers talked about their own child and family's experiences and reflected on the pilot transition clinic. The narrative audio-content of the interviews was transcribed and reviewed; the themes which emerged provided further support to the multi-agency and multidisciplinary format and was used to inform future clinic planning and sustainability.

Following the successful initial pilot, charitable funding for expansion of the project over 2 years was obtained from [Together for Short Lives "Improving Transition for Young People Fund"](#)¹¹. This allowed for mixed methods data collection over a 1 year period (April 2019-2020) with the aim of continuing to improve the service being offered and to secure long-term funding for the clinic.

Carers were invited to complete the [Health, Functioning and Wellbeing Summary](#) as part of their clinic appointment and 6 weeks later. The aim was to identify changes in the scores across health, functioning and wellbeing following multi-professional involvement in their care. Information on referral to or liaison with other specialties, changes to medication, discussion of advance care plans and admission prevention was documented prospectively by the transition nurse at each clinic appointment.

At the end of the 1 year pilot, data on A&E attendances as well as hospital admissions and length of stay were collected for patients who were part of the transition clinic and a comparison group of young adults with complex medical needs who did not meet criteria for inclusion in the pilot due to their age being >21 years or who declined taking part in the Pathways clinic.

Finally, feedback on the experience of the clinic was obtained from both professionals and carers. Professionals who had attended the clinic were sent an anonymous survey via email with the aim of understanding the impact on professionals' working time by attending the

clinic as well as to gather feedback to further improve the service. Carers were asked to complete patient feedback forms which were generic to the hospital trust.

Results

An initial pilot transition clinic for young people with complex medical needs took place for 6 young adults over a 6 month period. Present at each appointment included the young person and their carer(s), a Transitions Nurse, a Consultant General Physician with specialism in Movement Disorders, the young person's paediatrician, relevant allied health professionals and a member of the adult learning disability team. The young person's GP was also invited to attend. The joint clinic allowed for direct handover of care from paediatric to adult teams, with patients and families able to witness and contribute to this crucial communication. No additional funding or resources were available for this pilot, and clinic appointments took place in an accessible room on an ad hoc basis at the beginning of an established afternoon clinic list.

If the young people were acutely admitted to hospital, an alert on their hospital records flagged the need for them to attend a 'home ward', where the general physician worked and where the nursing team were experienced in caring for people with movement and other neurological disorders. Support for capacity assessments and palliative care was accessed where required. Carers also had access to direct telephone contact via the transitions nurse when needed, recognising the need for a single point of contact during this transition period.

Letters inviting parents to provide feedback were sent to all 6 sets of parents. Semi-structured interviews were completed with 3 parents of 2 young adults with complex medical conditions involving physical and profound learning disabilities. 8 themes emerged from conversations about experience of transition to adult services and how the new Pathways clinic could improve this experience.

1. Ongoing lack of clarity about general processes of transition
2. Vulnerability of the 'child' in an adult world
3. Parents are experts

4. Concern about the mismatch between the general levels of medical knowledge/skills and their child's needs
5. Parents want to be trusted and to build relationships
6. Parents want GPs to be in the loop but are uncertain about their disability skills and value specialist 'backup'
7. Parents value a single point of contact
8. Importance of continuity from outpatient to inpatient care

With further evidence of an unmet need and support from parents for the pilot project, the team secured funding from the Together for Short Lives "Improving Transition for Young People Fund"¹¹ to expand the project over a 2-year period. Funding covered clinic and admin time for medical and nursing staff (20x 3-hour clinics per year) as well as 1 day a week of admin support. Formal clinics were established in the community (community hospitals or special educational needs schools) to facilitate access for the young person, carers, social care and education team to attend. The project became known as the "Pathways Clinic" from this point on.

Data collection was planned for 12 months from the first clinic in May 2019, however due to COVID-19, face to face clinics were replaced by virtual clinics in early March and data represented below is therefore from May 2019 to March 2020 only.

14 clinics took place for 30 young people over 39 appointments (30 1-hour new appointments and 9 30-minute follow-up appointments). The average age was 18.83 years (range 17.45-20.12 years). The average number of diagnoses/patient was 5.36 (range 3-10). The most frequent biological system affected was neurological (85/161), followed by orthopaedic (27/161) and gastroenterological (20/161). Of the neurological diagnoses, the majority were made up of learning difficulties, cerebral palsy, seizures and visual impairment. Scoliosis was the predominant orthopaedic diagnosis and gastrostomy was the predominant gastroenterological diagnosis (figure 3).

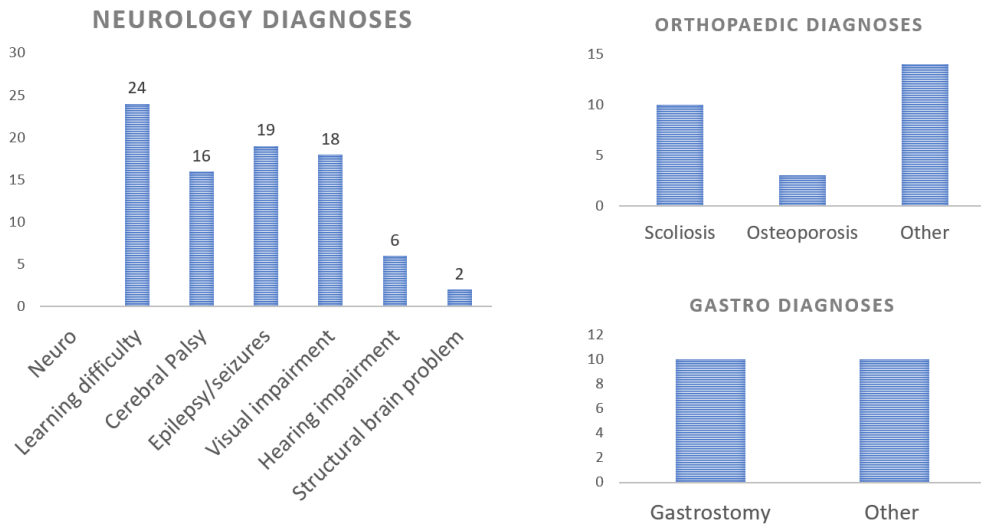


Figure 3. Distribution of frequency of diagnoses affecting young people in the Pathways clinic.

Clinics were attended by professionals and carers from >14 disciplines and agencies, including medical, nursing, education, social care, allied health professionals and residential care (figure 4).

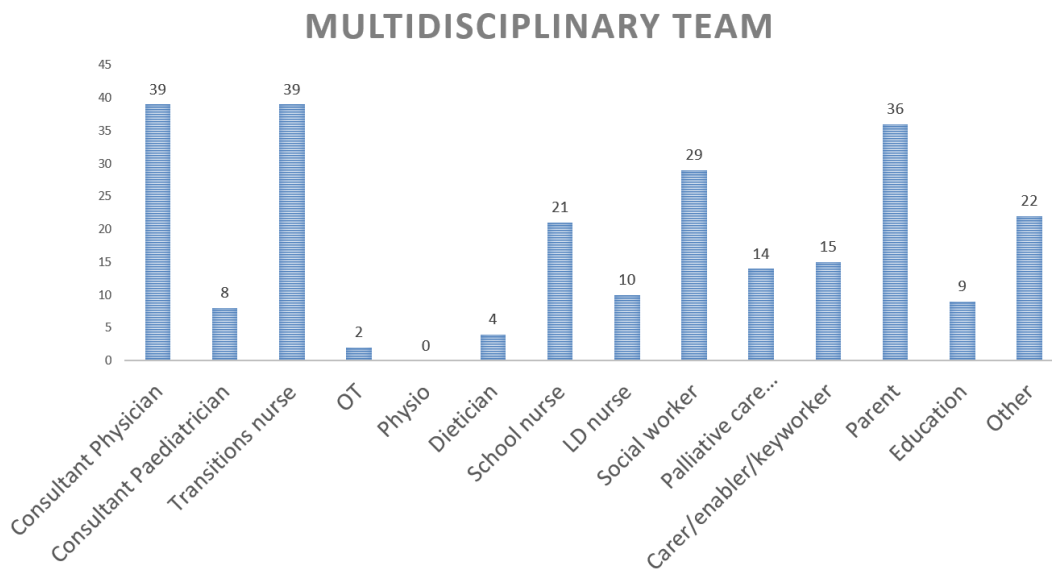


Figure 4. Distribution of frequency of multidisciplinary team members attending the Pathways clinic.

18% of patients had an Advance Care Plan (ACP) in place, 84% had a hospital passport, 81% had an Access Support Card and an additional 50% were added to the Learning Disability Register. Changes to medication were made in 26%. Referral to or liaison with another specialty was required in 64% of appointments. In 2 cases, admissions were avoided after

the clinician identified planned admissions for investigations (e.g. dental work and MRI under general anaesthetic) which were then organised to occur simultaneously. Health, Functioning and Wellbeing scores were completed as part of the clinic review for 25 patients at their first appointment, 8 patients 6 weeks after their first appointment and 9 patients at their second appointment. The average number of carers reporting “no concerns” increased at each timepoint while the average numbers reporting “some concerns” and “serious concerns” decreased from the first appointment to the second (figure 5).

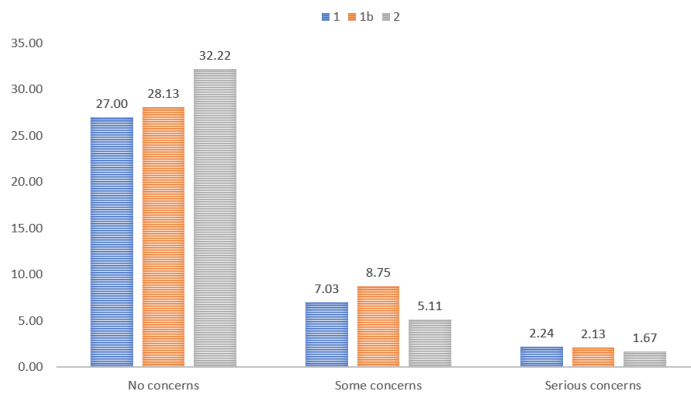


Figure 5. Mean scores on Health Functioning and Wellbeing forms at initial appointment (1), 6 weeks post first appointment(1b) and at second appointment (2).

When the scores were broken down into ‘health concerns’, function concerns’ and ‘wellbeing concerns’, the trends were similar, with the most marked improvement in the function scores (figure 6). The changes in the scores were not statistically significant for any of the areas or timepoints.



Figure 6. Mean scores on Health Functioning and Wellbeing forms at initial appointment (1), 6 weeks post first appointment(1b) and at second appointment (2)

Data on A&E attendances, hospital admissions and length of stay for patients in the pathways clinic and comparison group did not show any statistically significant difference and has not been detailed further here.

Anonymised online feedback about Pathways Clinic was completed by 19 MDT participants from disciplines including medicine, nursing, occupational therapy, dietetics, education and social care. While participants felt that on average, their attendance at the clinic appointment took 12% more time than a regular appointment, they still considered it was an effective use of their time (average score 7.4; 0 = least effective use of time, 10 = most effective use of time). Participants felt that the clinic improved patient care (average score 8.9; 0 = definitely not, 5 = same level of care, 10 = definitely improved) and promoted multidisciplinary working (average score 9.6; 0 = did not improve MDT working, 10 = improved MDT working). The main reasons for stating the improvement in patient care included allowing a 'robust handover with information sharing within the MDT' (including safeguarding), 'facilitating a patient and family-centred approach to care' and 'providing a clear route for ongoing support into adult services.' Challenges highlighted included uncertainty about the future of the clinic, increasing appointment time, ensuring the environment is appropriate for the patient, extending the inclusion criteria for the clinic, promoting greater representation from social care and streamlining the clinic for the professionals (e.g. grouping patients for a specialist).

Parent and carer feedback highlighted that the clinic was efficiently organised and run. Carers felt the team listened to and understood their concerns as well as providing solutions and suggestions. Carers valued having the appointments within the school setting. The main concerns raised were about the clinic rooms being too small for the number of people and uncertainty of the clinics continuing long-term.

Discussion

We created an expert multi-disciplinary team within secondary care by combining skills from community child health, transition, palliative medicine, general medicine and

movement disorders. We hypothesised that by streamlining healthcare coordination, we could positively impact the following areas:

1. Better health and quality of life outcomes, with a focus on prevention of crises and advance care planning
2. Reduce the number of hospital appointments required where multiple adult teams might have been involved in caring for multi-system disorders (being more acceptable and achievable for patients, and reducing demand on other hospital outpatient clinics)
3. Improve inpatient experience through development of a familiar environment (a 'home-ward') and care from a team that knows the patient
4. Have 'one point of contact' - for patients, families, carers and other health and social care professionals, with the expertise required to manage sometimes rare and complex clinical conditions to improve patient outcomes as well as help to avoid unplanned hospital admissions.
5. Target case-management from the point of admission to hospital by the expert team to help reduce length of stay in hospital and support hospital staff to deliver high-quality care.

The advent of the COVID-19 pandemic forced dramatic changes to outpatient services throughout the NHS and the Pathways clinic was no exception. The discontinuation of face-to-face clinics affected the MDT nature of the service but did not alter the fact that young people had a named consultant and single point of contact for any concerns. The change to the service meant data collection was discontinued early, thus reducing the already small number of data points. Our quantitative results do not show any statistically significant improvements in clinical outcomes, but we hope to continue this now services are returning to a new normal. As relationships continue to strengthen between families and the adult MDT, we hope to focus on advance care planning and closer working with the palliative care team.

We were delighted to secure long-term funding from the Royal Devon and Exeter NHS Foundation trust to continue this vital service and are now planning the post-covid recovery. We would encourage other centres aiming to improve transition services for young people

with complex medical needs to take a similar approach to ours, recruiting an enthusiastic team to pilot small changes, utilising charitable funding to expand and gain evidence to support business cases for long-term solutions.

It's like a car MOT – You wouldn't miss that would you? It would be silly and it would cost a lot more in the end you know!"

[Parent carer during semi-structured interview discussing the value of annual review appointments with adult physician]

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