chAS
Children’s Hospices Across Scotland
Innovative Models of Transitioning from Children’s to Adult Palliative Care Services

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Objectives of this session:

- Update of some of the work being undertaken by Children’s Hospices Across Scotland (CHAS), and increased data collection
- Put this in context of transition
- Discuss the meaning of the word transition
- Answer the question!
- So what about transitioning from children’s services?
ChAS
Children's Hospices Across Scotland
Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)

- More children with palliative care needs
- Children under 1 year a priority
- Age specific services for 16-25 year olds
- Services to ensure access to care in areas of higher deprivation, be culturally sensitive
- Improved psychological, emotional and domestic support
Referrals Received 1 April 2016 - 31 March 2017

- Under 1
- 1 - 5 years
- 6 - 10 years
- 11 - 15 years
- 16 - 20 years

- Under 1: 33%
- 1 - 5 years: 14%
- 6 - 10 years: 15%
- 11 - 15 years: 32%
- 16 - 20 years: 6%
The challenge for CHAS

- To increase its REACH to more BCYP in Scotland with LL/LTCs
- Provide for increasingly higher numbers of children < 5 years old
- Consult with key stakeholders, parents and staff about introducing an upper age limit
- Decision taken: 21 years (20.99)
- Seek funding (BIG Lottery monies) to construct a Transition Team for 3 years
- Remit: support the transition of young adults from CHAS to adult lives and age appropriate care.
▪ Initial phase of work to focus on working with young adults over 21 years of age
▪ Regulator had also confirmed that upper age limit would be 21
▪ January 2015-18: 130 in transition from a varying 310 - 600 (>25%)
▪ 29 (29/130) young people died (23%) in this period
▪ 26 male, 3 female
▪ Diagnoses?
Diagnoses of those who died

- Duchenne muscular dystrophy+++ 
- Cerebral palsy 
- Down’s syndrome 
- Friedreich’s ataxia 
- Mitochondrial myopathy 
- Brain stem glioma
3 key outcomes (BIG)

- Young people with LSCs will have increased opportunities for autonomy
- Young people with LSCs will have improved access to appropriate services in their communities
- Families which have young people with LSCs are better able to cope with their caring roles as they move beyond CHAS
Each outcome measured by key indicators with tools

- Evaluation wheels
- Questionnaires (onset and discharge)
- Transition assessments and plans
- Care file recording
- Verbal feedback from families

- Moving to a formal evaluation to.............
Formal evaluation

- Examine whether the teams have achieved its outcomes
- Consider the impact on CHAS
- Identify the key emerging themes for learning
- Look at and improve the processes and pathway for CHAS when working with young people in transition in the future.
- Consider the impact of this work on wider networks which support young people
- Moving to a summative evaluation at the end of the project (December 2017)
BIG meant 6 monthly reporting:

Role of transition worker:

- Seek alternative respite and short breaks
- Link with adult hospices/palliative care services
- Engage with local authorities to secure/increase statutory funding
- Specific health needs and information provision
- Find leisure and learning activities in local community
- Help build social networks and new relationships
- End of life care planning – information to help complete anticipatory care plans (ACPs)
- Referrals to other agencies (eg vocational training schemes, education provisions)
- Advocacy
- Education, training and work
The Transition Team worked individually with each YP – captured in the assessment proforma

Done for all YP (all but 2 who declined to engage)

Aims met as all YP and their families were offered a service from outside CHAS

Several families displayed anger and negative emotions – but did engage and then benefitted from the engagement, eg increased social work benefits, signposting, links with adult palliative services
Learning: significant for CHAS

- Improved transition pathway has evolved with specific protocols
- Adoption of processes and timescales to ensure effective timely transition planning
- Work now must continue prospectively for those over 18 years
- Confidence in staff members is increasing so some conversations beginning at 14 years (Scottish Transition Forum’s 4 Principles of Good Transition shows that the earlier the process begins, the more successful are its outcomes)
Respite/short breaks – one consistent area of need >21:

Summary of work showed:

- “One size does not fit all”
- Range of short breaks is essential = choice
- National shortage of specific buildings to provide respite services for YP with complex needs
- YP with complex needs often needed health professionals on site
- People’s individual budgets varied across different regions.
Young People’s Goals

- “I would like to meet other young people in my community.”
- “I would like to complete my college course and write my own blog....and to manage my own finances.”
- “More active social life.”
- “I would like to have a girl friend.”
- “I want to live independently.”
- “I want to find more information about travelling by plane.”
Health transitions

- Only a small number indicated that moving from paediatric to adult services had been smooth
- Most had found it cumbersome and stressful
- Some adult healthcare staff represented that they did not have sufficient knowledge of people with such disabilities.
- Some felt that some paediatricians were reluctant to move patients onto adult services – some praised the paediatrician for this....and one was still having care at 27 years.
Adult palliative care:

- Early referral allows a smooth transition from CHAS and this should be accompanied by a full medical referral from CHAS doctors
- Early engagement offer reassurance to YP and parents
- Adult hospices can replace CHAS as “one stop shops” for patients, carers and so provide supportive relationships
- Going to adult hospices distil fears
- Enables adult services to embrace becoming a lead role in ACP
- Continued input from CHAS medics
What differences did the project make?
Were there unintended consequences?

Approached by Nordoff Robins Music Therapy Service as it sought funding to develop a bespoke service for YP in transition.

Finale “showcase” event had not been planned but was demanded to show the positive can-do people-focused work

The freed up places -> increasing 0-5 year cohort
Cross Party Group Meeting
Thank you for listening........................

Any questions?