ACT

Valuing short lives

Transition: Pieces of a jigsaw: Fitting it together, working across boundaries.

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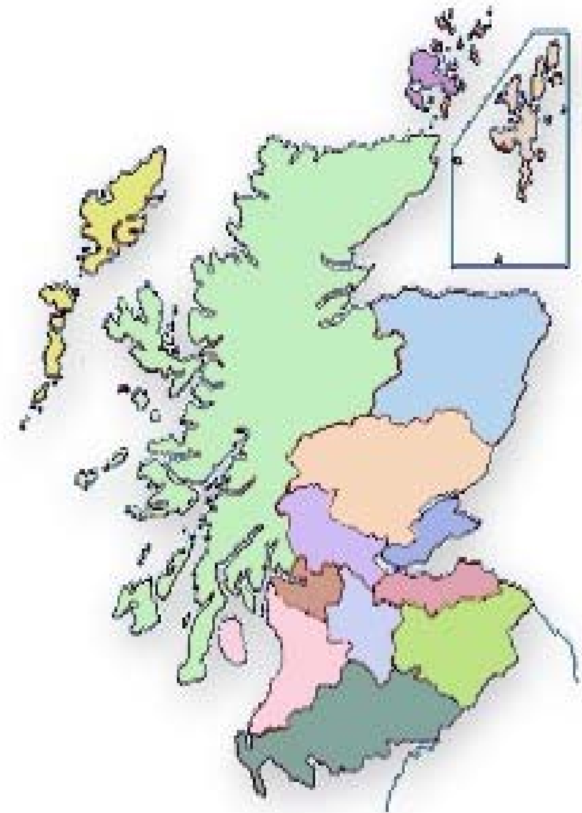
Warnings

- Scotland is different.
- This is "work in progress".
  - My metaphors are murder!
  - Please contribute.

Scotland is different….

- A third of the UK but less than a tenth of the population.
- 787 islands.



NHS Scotland is different.

- 14 Health Boards, Community Health Care Partnerships.
- No purchaser/provider split.

Scotland is different …2

Strategic direction.

- Scottish palliative care strategy - Living and Dying Well 2008 – no mention of children or transition. Not the equal of Better care better lives in England.

- Better Health Better Care 2009 – National delivery plan for children & young people's specialist services. £32 m investment over 3 years. Acknowledges improved survival of children with complex needs & challenge of transition.

- Continuing care guidance Feb 2008 – no mention of transition.

Work in progress.

- Scottish Children & Young People's Palliative Care Network.
- 4 Children's palliative care nurse consultants.
- ACT Transition Coordinator.
- Transition sub-group.

  First step: map 'transition practice' in Scotland identifying good practice and gaps in provision.

Transition to adult services – one of many transitions…

“I have been fighting from the day my daughter was born and I’m still fighting. I am very, very tired”.

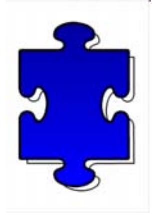
“We had to put the ‘battle gear’ on – but 50% of families cannot do this”

The many transitions in health, education, housing, social care etc affects family expectation and ability to manage the systems.

Piecing together the Transition Jigsaw

Sorting the pieces

Personal



Strategic

Operational

Personal & interpersonal

- Put the young person at the centre of transition planning.
- “Build the young person’s awareness of choice and voice”
- Information & communication:.
- Letting go “often we are waiting for the paediatric neurologist to let go of the young person”

Person centred planning

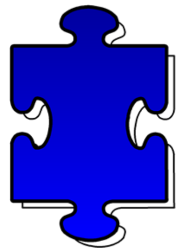
"Support should be based on what kind of life you and your relative want to live, rather than what service your family might fit into

….It is about finding how to enable people to be full citizens of their local communities"

Together we're better EDG

Thinking point….

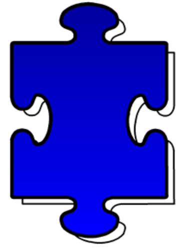
How do you ‘plan for adulthood’ while planning palliative care?



Strategy

" The welcome improvement in the survival of children with life limiting, and often complex, conditions raises specific challenges. In the past children with such conditions frequently did not survive to adulthood. As a result training and configuration in adult medicine is not designed to meet their needs" Better Health, Better Care 2009

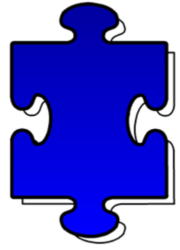
Can we build transition services on the needs, priorities & preferences of young people and families?



Developing a Transition policy & pathway

A rural health board:

- Strategic group established.
- Multi-agency project group chaired by the Medical Director.
- Seconded a senior nurse for 6 months.
- Consultation with young people & families.
- Development of policy and care **pathway**.
- Health staff to support implementation.



Key points

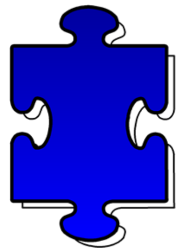
'**Ownership**' of Transition policy at senior level in health and social care organisations.

Raised the profile "We are getting Transition spoken about"

Health trouble-shooters: Named medical leads in adults & paediatrics.

BUT

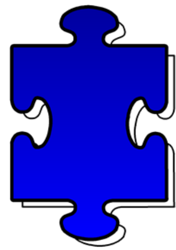
Tertiary centres fail to utilise local processes – They "extend their hospital corridor into the community".



A Vision for Transition - Highland

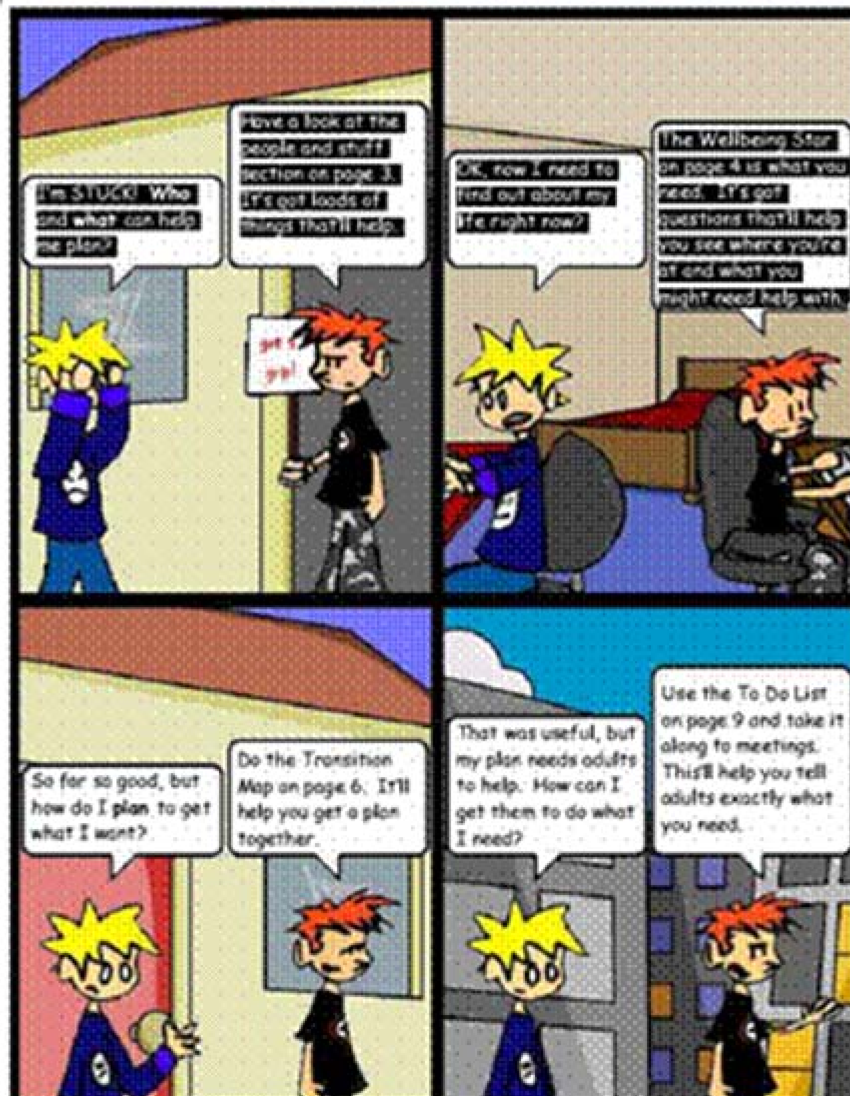
A multi – agency project to improve the transition process for all young people with additional support needs and those at risk of not moving on to a positive post school destination.

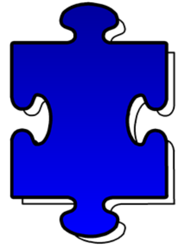
- 50 young people asked about their experiences of transition. Tracking study. Questionnaire for Professionals
- Transition map & checklist to support person centred planning.
- Its my choice – information & advice
- My Transition Guide
- Transition policy & procedure.
- Dedicated transition coordinator.



My Transition Guide

Highland





Continuing care

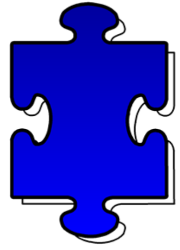
The Children's Continuing Care forum -
"Transition is a nightmare"

A Rural/urban Board.

Joint paediatric & adult complex care service – same principles, same staff, same budget.

"All packages 50:50 funded health/social work".

Complex care Transition is not an issue.



Thinking point

Should we have local Transition strategies for all, or condition specific approaches?

Operational

“ We had no structured advice on how to proceed. There was a lack of coordinated information”.

“We had to re-invent the wheel”

“Once again we had to start from scratch”

Some parts of the jigsaw

- Transition Pathways.
- Keyworking: “Identify a person for each young person…. and their family to help build bridges between children’s and adult services”. E. Lothian 2005
- Transition teams or specialists.

Condition specific transition

The most frequently cited examples of good transition planning are for condition specific services :

- Cystic Fibrosis
- Diabetes
- Rheumatology

The CF Team

"10 years ago there was no Transition planning, The adult consultant would meet with a young person, make them cry & go away again. It was a mess"

- Sent a questionnaire to all of the teenagers and parents. Followed this up with further consultation.
- Presented the results to the adult service and eventually won them over.
- BUT – it is driven by the nursing team.

Independent advice & advocacy

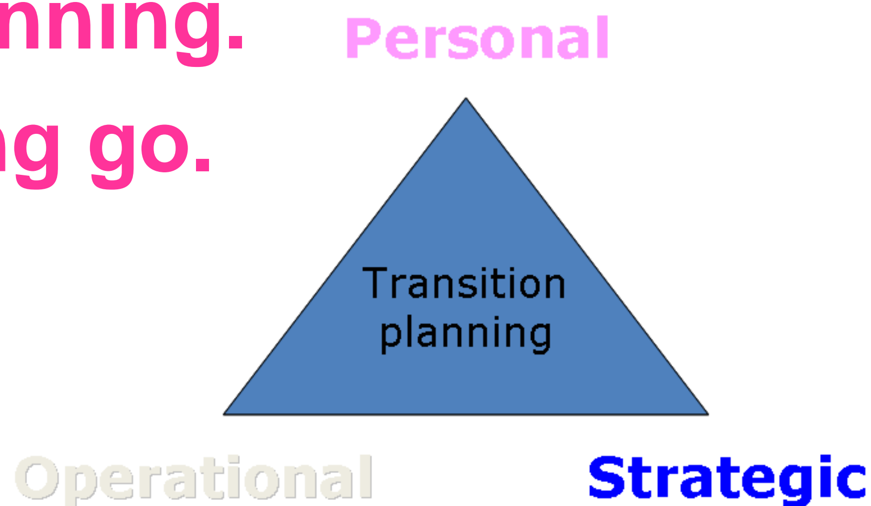
Signpost: advice, directory. Transition, awareness & education sessions for families. Youthwork with socially isolated young people.

EDG – Edinburgh Development Group: Person centred planning.

Pamis Futures Project: Keyworking and person centred planning. Assist with ALL aspects of the young person's life that may be affected at transition - not just leaving school. Transition Planner , library, communication passports.

Naming some of the pieces

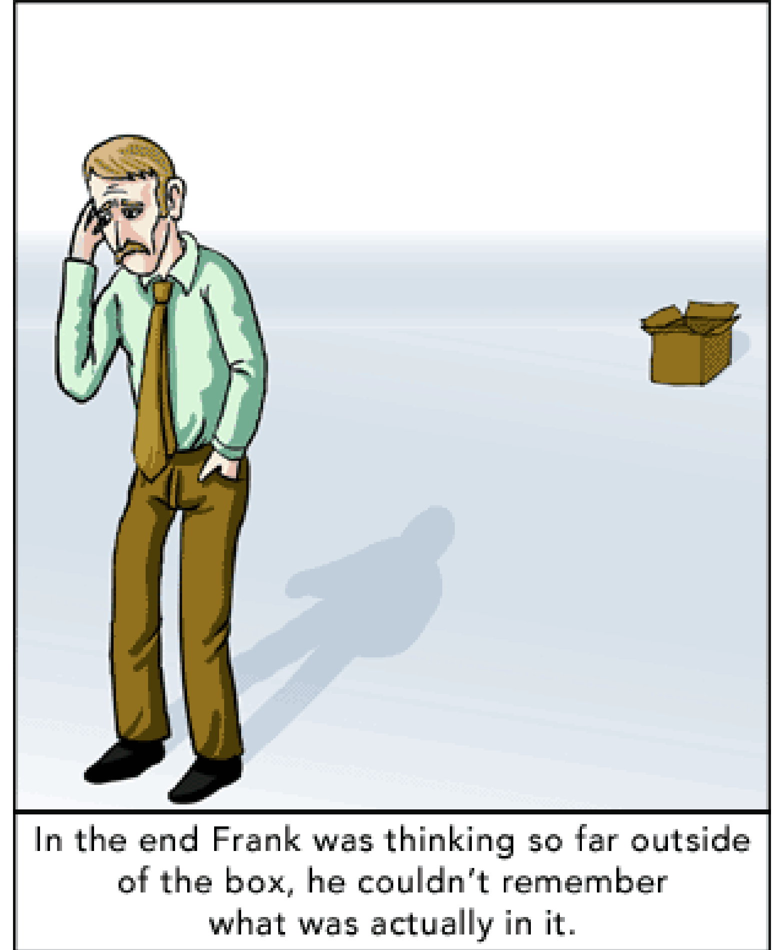
- Person centred planning.
- Preparation & letting go.
- Ownership
- Consultation
- Resources
- The multi-agency pathway.
- Keyworking
- Independent advice & advocacy



Joining the pieces

Transition should be...

- **integrated, seamless and person centred.**
- **a cause for celebration not grief.**



Thank you!

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