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Transition: what young people and parents are saying



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Transition

- ◆ Preparation for transfer
- ◆ Transfer
- ◆ Engagement with adult health service

Pediatric & Adult Care

Two Different Cultures?

PAEDIATRIC

- **family consultation**
- **multidisciplinary team**
- **specialist knowledge**
- **fewer patients**
- **shorter waiting lists**
- **peer support**
- **fewer costs**

ADULT

- **individual consultation**
- **limited team support**
- **lack experience rare conditions**
- **large patient numbers**
- **few young adult clinics**
- **financial issues**



Adult health services

- ◆ Age appropriate preventive and primary care
- ◆ Sexuality, fertility and reproductive health
- ◆ Promotion of an active role in health care
- ◆ Access to subspecialties to treat adults



Transition support

- ◆ Orientation
- ◆ Information
- ◆ Identification of health services
- ◆ Advocacy
- ◆ Problem solving
- ◆ Follow up

Referrals

Cystic Fibrosis	16
Asthma	1
Brain Injury	5
Haemophilia	2
Thalassaemia	2
Immunology	1
Connective Tissue Disorders	1
Neuro/Epilepsy	3
Cerebral Palsy	2
Renal	4
Spina Bifida	5



Interviews



- ◆ 42 referrals
- ◆ 60 interviews
 - 32 with young people
 - 28 with parents



Interview questions

◆ Overall experience of transition

- Tell me about your transition

◆ Preparation experienced

- What preparation did you receive to transition?

◆ Preparation wanted

- What was most helpful?
- What could have been done to help prepare you better?

◆ Information wanted

- What were you told about transition and adult health services?
- What did you want to know about transition and the adult health service?



1. Apprehension

- ◆ *I thought it would be hard but it was easier than I thought*
- ◆ *Not as bad as I thought it would be, staff make it sound bad*
- ◆ *I thought it would be confusing but I found it quite easy*



2. Environment

- ◆ *I was so used to a clean hospital*
- ◆ *More comfortable at the childrens hospital*



3. Inevitability

- ◆ *I was prepared personally, I was expecting it*
- ◆ *Just something I had to do, not really a problem*



4. Differences

- ◆ *It was totally different, the people, the doctors, the hospital itself*
- ◆ *It is nothing like the childrens hospital*
- ◆ *It is ok, pretty close to how they do things*
- ◆ *It was good, pretty easy, much the same*



5. Meeting new people



- ◆ *Challenging to meet new people and to trust new people*
- ◆ *A bit scary, but I got to know the people so it's getting better*
- ◆ *I had met the doctor when I was young*
- ◆ *I thought I would have to meet a new doctor but I didn't so it was ok*



Transition rating

1 = no problem

4 = problematical

1 37%

2 50%

3 13%

4 0%



Preparation

- ◆ Meet the new team
- ◆ Information about how clinics run, where to go, when to come to clinic, how to get there and a map
- ◆ *Being shown around, meeting the people that were involved in my care was good because then I recognised them*

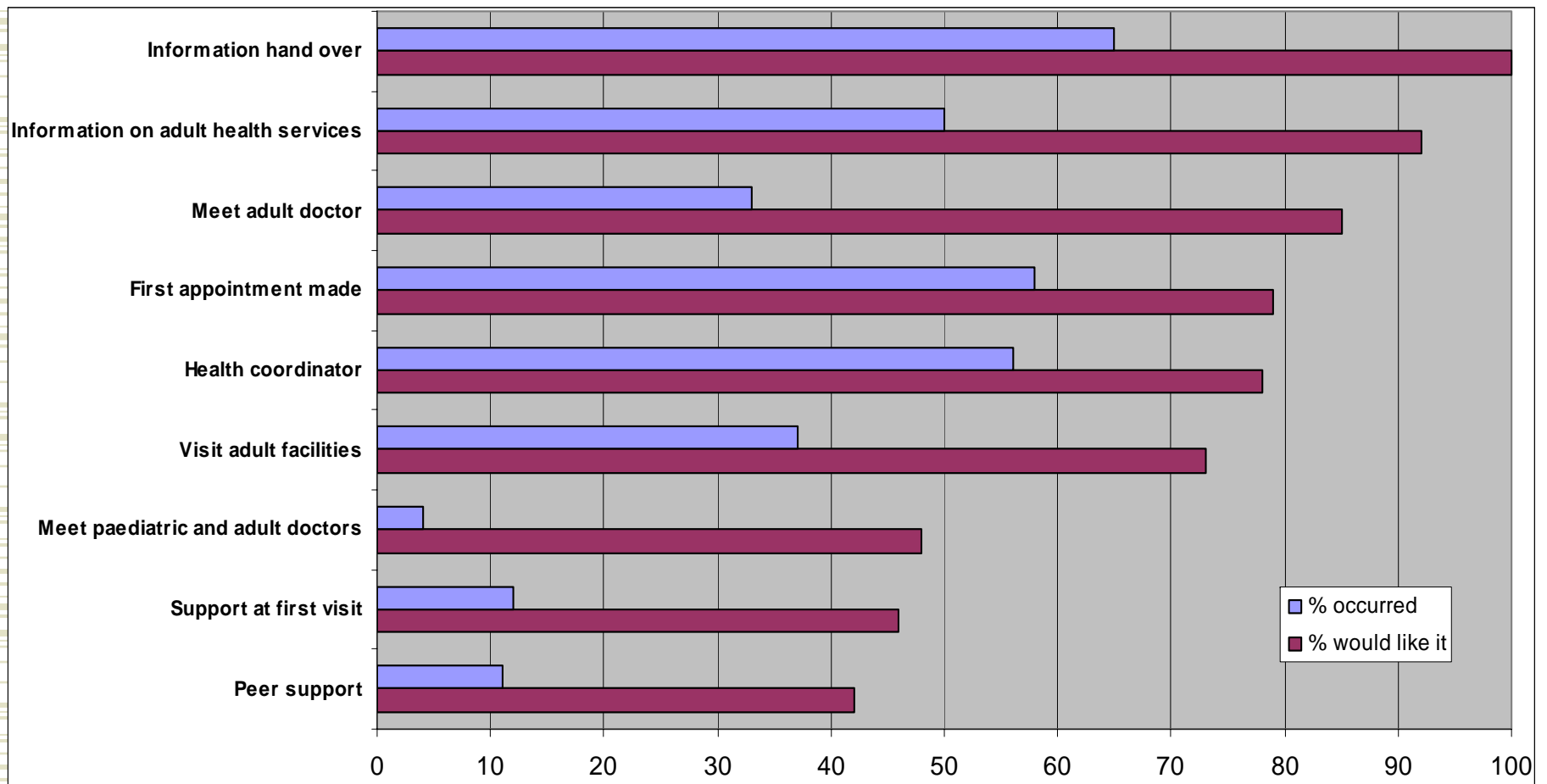


Self management



- ◆ *Practised going in by myself to see the doctor last year, mum would come afterwards*
- ◆ *Having part of the appointment by myself was good*
- ◆ *Practise making your own appointments*
- ◆ *Collect own medications from pharmacy*
- ◆ *Practise staying without parents at night (while still at childrens hospital)*

What young people want





When to bring up transition



- ◆ Range of times from 1 month to 2 years before transfer
 - 55% < 6 months
 - 30% 12 months
 - 15% 2 years

How to inform about transition

- ◆ Talk 50%
- ◆ Written 30%
- ◆ Visit 16%

- ◆ *Would read if it was straightforward*
- ◆ *Information sheet, not too much information*



1. Better than expected



- ◆ *Went well, we were apprehensive, build up fears, worry about nothing*
- ◆ *Found it rather good once we got into it*



2. New team



- ◆ *Chose because we already knew the doctor*
- ◆ *Good, we liked the doctor we saw*
- ◆ *I think the main thing is to get a caring doctor*



3. Leaving the childrens hospital

- ◆ *Didn't find it hard to go to the adult service but found it hard to leave the childrens hospital and leave the staff there, leaving the security*
- ◆ *Bit sad to leave..... and now we have to go to another doctor*



4. Changing role



- ◆ *I don't feel as needed now, that is hard to adjust to*
- ◆ *I miss not going to clinic appointments*



Transition rating



1 = no problem
4 = problematical

1	41%
2	30%
3	11%
4	18%



Positive comments

- ◆ *It's worked very well for us*
- ◆ *I just wish we'd done it sooner*

Negative comments

- ◆ *Really wasn't a transition, we were dumped*
- ◆ *It's been a nightmare, not for but for me*
- ◆ *It stinks, it was really hard, mainly rehab the hardest, physios, OTs*
- ◆ *If you don't think about yourself, no one really tells you (about services)*
- ◆ *A lot of parents out there don't know which way to go*

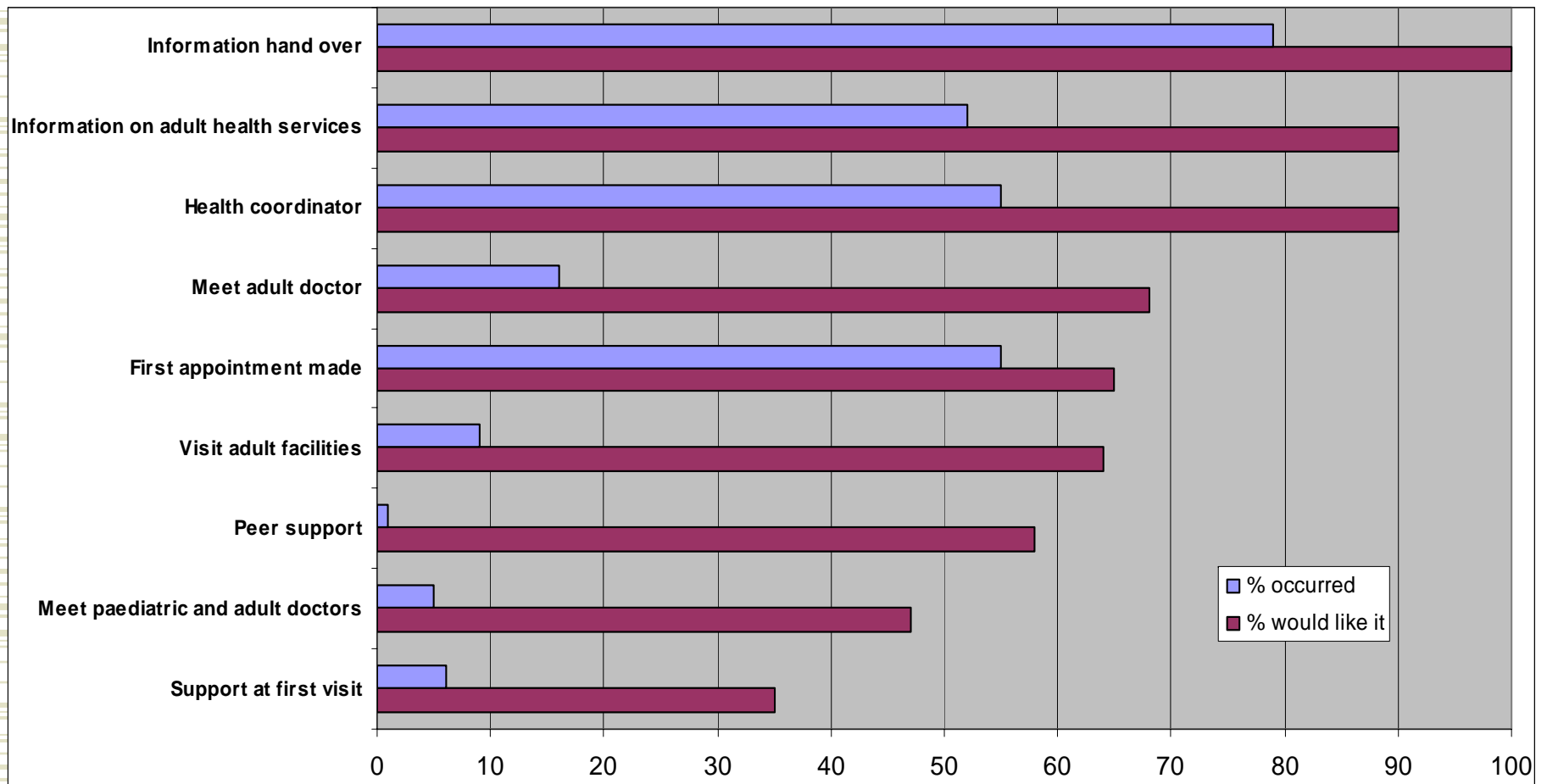


Preparation wanted

- ◆ Information about adult health services
- ◆ What to expect
- ◆ Where to go, where to park
- ◆ How the clinics run

- ◆ *My biggest fear was getting there and finding the place*
- ◆ *A guide of where to go, what to do and what to expect*

What parents want





When and how to raise transition

- ◆ 90% said 12 months to 2 years before transfer
- ◆ Talking 45%
- ◆ Written 30%
- ◆ Visit 20%



Summary

- ◆ Talk about transition, with practical written information
- ◆ Talk about differences without negative spin
- ◆ Offer range of transition practices
- ◆ When – 12 months to 2 years before transfer



Summary

- ◆ Young people
 - Good handover of information
 - Information about the adult service
 - Meet adult doctor/team before transfer

- ◆ Parents
 - Good handover of information
 - Information about the adult service
 - Someone to coordinate the transition



Summary

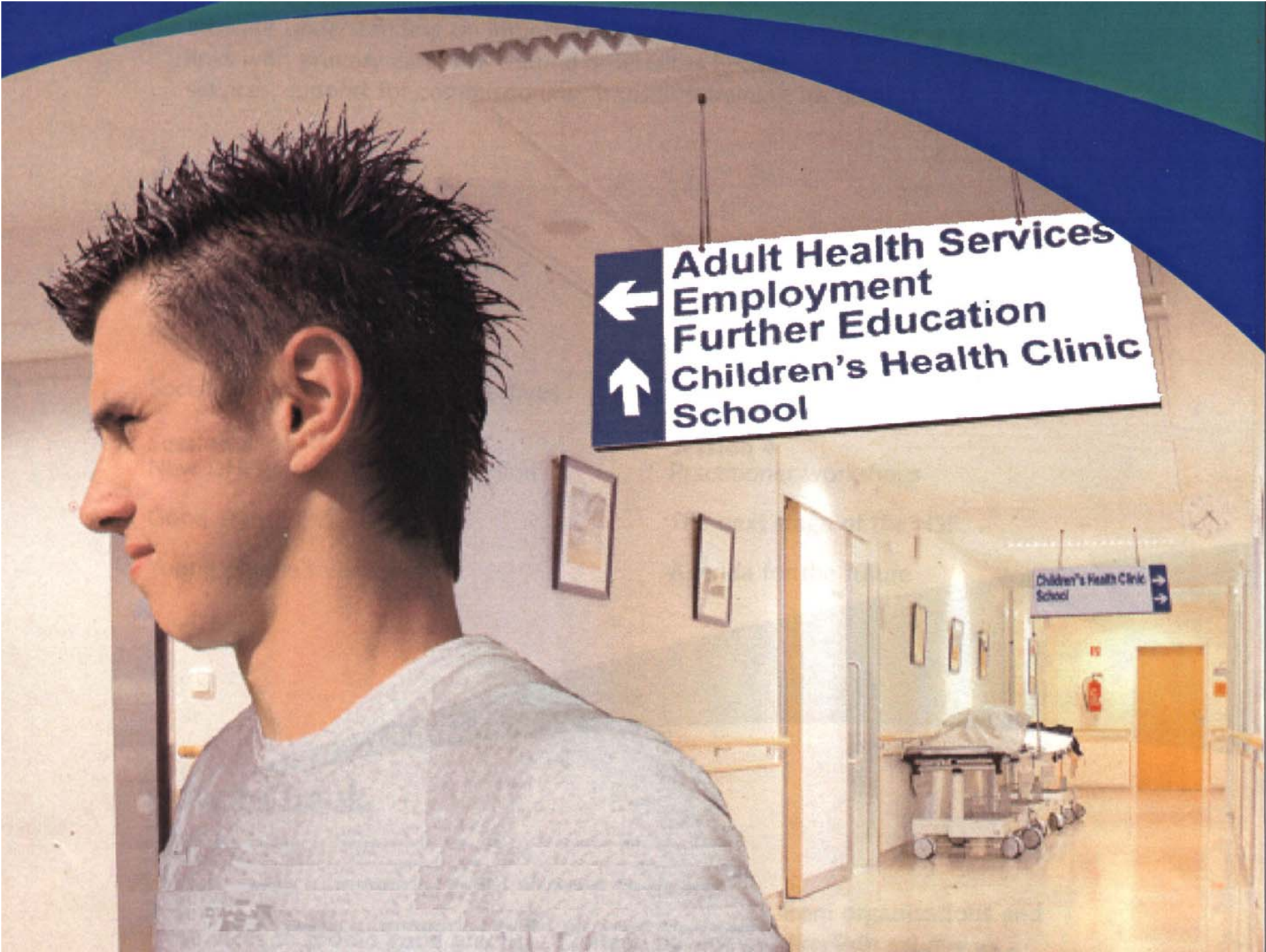
- ◆ The majority of young people and parents don't have a problem with transition
- ◆ Problems that do exist are systemic mostly about lack of services in the adult system



Strengths of project



- ◆ Able to interview participants
- ◆ Interviewed before memories faded
- ◆ Not just one adult facility



← Adult Health Services
Employment
Further Education
↑ Children's Health Clinic
School

Children's Health Clinic
School →