



Transition focus group

Thursday 16 April 2015, 10-11.30am, Sheffield Mencap & Gateway

In attendance: 16 parents of young people with SEND, Dee Desgranges (Assistant Director, Lifelong Learning Skills & Communities), Dalia Magrill (Sheffield Mencap), Anne Snowdon and Eva Juusola (Sheffield Parent Carer Forum, notes)

Background: Over the past few years, the Sheffield Parent Carer Forum (SPCF) has been involved in a number of projects and consultations around the transition to adulthood; for example, the transitions template developed by John Hill in 2011, the "Progressions programme" led by Nick Partridge in 2012, and focus groups with Cllr Jayne Dunn and Ed Sexton in the summer of 2014. All of this work was useful in gathering parental feedback, but it did not translate into tangible improvements on the ground; our "State of Sheffield 2014" survey showed that parents continue to experience the transition to adulthood as a difficult and stressful process.

Feedback gathered through previous consultations provided a starting point for our discussions, which focussed on finding solutions to the issues raised. Proposed solutions have been split into three categories: 1) information/communication, 2) processes and 3) provision.

Sheffield City Council is in the process of creating an integrated 0-25 SEND service, and feedback from this session will be used to shape the new service.

Issues relating to all services

1. Unresponsive services

Parents often complain that it takes many emails and voicemails to get a response from key services, such as the Transitions team or SEN Assessment and Placement team. When they do manage to make contact, they sometimes feel that there are being passed from "pillar to post", with nobody taking responsibility.

Information/communication: Publish target response times in email signatures, answerphone announcements etc. and encourage customers to complain if these are not being met.

Processes: The Council is aware that some services are not meeting their performance targets, and is monitoring these closely. Teams are currently being restructured to create a single 0-25 SEND service, which will include the SEN Assessment and Placement Team, Transitions Team, Early Years Inclusion Service, Children with Disabilities Team, and SNIPS. This service will have a single front door and operate a triage system to ensure that urgent cases are addressed promptly.

Referral and signposting processes should be reviewed to ensure that families don't fall through the gaps (e.g. through effective follow-up).

2. Decisions are made by separate panels, who fight over who funds what, leading to long delays

Parents who had contacted adult social care early on to ask for an assessment were told to wait until six months before the child's 18th birthday. However, in many cases the process took a lot longer, as their child's case was passed from panel to panel.

Information/communication: Parents should be encouraged to request an assessment earlier; the six-month limit should be scrapped until a faster decision-making process is in place.

Processes: Work is ongoing to create a joint decision-making process with children's and adult health, education and social care. The Council hopes to create aligned budgets with Health. Officers will be given authority to make small-scale funding decisions on the spot, without having to refer the case to a panel, which should speed up the decision-making process.

3. Lack of information about transition processes and options available

Parents find that information about transition is inconsistent, frequently out of date, and incomplete. Being advised by people with half-knowledge is dangerous, but this happens a lot at mainstream schools. Parents of youngsters in mainstream settings feel very isolated.

Working parents of young people who are not safe to be left on their own need to know several months in advance what their young person's timetable will look like, and when terms start and finish. Colleges need to be aware that last-minute timetable changes can cause huge problems for these families.

Information/communication: There needs to be a single, authoritative source of information for everyone – the local offer. The local offer website is a work in progress, and needs to be shaped in partnership with parents and young people, to ensure it contains the information they need, and is easy to navigate.

Parents specifically requested the following pieces of information:

- Blank EHCP template
- Term time starts and finishes in last year at school and at college
- Provision for young people during the summer
- Weekly timetable at college
- Day services for young adults
- The full range of post-16 education, e.g. New Routes, My Learning My Way, Kenwood House and Yew Tree Lodge, enrichment programmes, supported internships
- When and how to request an assessment from adult social care, and how to prepare for this

Information should be provided proactively and in timely chunks, e.g. via a transition timeline, or booklets for specific year groups. It should be holistic and include information about legal and financial aspects of transition, e.g. Mental Capacity Act, appointeeship, wills and trusts etc. A transition newsletter would be useful.

Processes: Develop a protocol which sets out what kind of information needs to be provided when, and by whom (schools, colleges, Sheffield Futures, or the SEN Assessment and Placement Team).

For example, this should set out that at the start of Y11, Y12 and Y13, schools must provide written information to parents and young people about college courses (content, entry requirements, progression routes, no. of days/week, support available, how to apply), a timetable of transition events, term time starts and finishes, and decisions and choices to be made.

School staff (particularly SENCOs in mainstream schools) need more training around transition processes.

4. Lack of accountability (panels)

Parents don't normally find out who sits on the panels that make decisions about provision their young person, and decisions are not always communicated in a clear and timely manner.

Information: Publish information about all relevant panels on the Local Offer – who sits on them, how often they meet, how decisions are communicated. Consider inviting parent carer representatives onto panels as observers.

5. Onus on parents to drive the process, leading to carer burnout and young people slipping through the net

Some parents find that navigating the transition process is so time-consuming that they have to give up work. They would like to have a named person / keyworker to guide them through the process and provide practical support.

Parents reported different experiences with the keyworking model. Where keyworking was an add-on to an existing role (e.g. SEN officer), that person did not have capacity to provide effective support. Independent support provided by Core Assets, on the other hand, was regarded very positively, as the person had sufficient capacity and was "not part of the problem".

Process: Parents would like an independent supporter for the transition process.

6. Confusion about application of Mental Capacity Act (MCA)

Both parents and professionals struggle to understand what the MCA means in practice. Parents may feel they are being sidelined by professionals, who suddenly expect the young person to make

decisions which they may not fully comprehend – for example, about medical treatment, or which exams to take or which college courses to apply for.

Process: Provide training for senior professionals (head teachers, SENCOs, SEN officers, service managers) which focuses on embedding MCA principles in their internal procedures, particularly in relation to involving parents of young people who lack capacity.

7. SEN transport

SEN transport policies can create barriers. For example, a parent said SEN transport were refusing to transport her young person from school to a private post-18 respite provider because they will only drop off and pick up from council-run homes. This rigidity does not support choice and leads to duplication (in this case, private taxi and escort funded by Social Care).

Process: Amend SEN transport policy.

8. Services not recognising each other's assessments, leading to duplication

Not discussed.

Issues related to Education

9. Lack of personalisation and focus on life outcomes in further education

10. Insufficient independent living training

For some young people, life skills courses are too basic and vocational courses too advanced. Colleges don't allow these youngsters to "mix and match", as they are funded for qualifications, not flexibility.

There is a limited choice of enrichment programmes, which don't always support young people towards employment outcomes.

Process: Use DfE funding (£35,000) to develop supported internships. Use outcomes in EHC plans to develop provision for young people coming up through the system.

11. Impact of 3 or 4-day week in education on parents' ability to work

The move from a 5-day week at school to a 3 or 4-day week at college can present huge problems for working parents.

Provision: The Council is working to make post-16 provision more equitable. They have commissioned enrichment activities for 16-19 year olds with learning disabilities, e.g. creative arts, art therapy, leisure activities, clubs run by Sheffield Futures. These provide a “fifth day” of learning and could continue into adulthood.

12. No contingency planning

If an educational placement fails, there is no “plan B”. The whole process starts all over again, which usually means that the young person spends a long period at home, which can take a huge toll on the whole family.

Provision: The Council is developing new provision at Yew Tree Lodge and Kenwood House for young people in KS and KS4 with ASD and mental health difficulties. This would provide a “safety net” if placements broke down.

13. EHC plans cease when a young person leaves education

Parents said that young people may need to leave education due to health difficulties and return when they are better, or they may need to be in a therapeutic environment after school and go to college later.

Process: There needs to be flexibility in the system to pause and re-activate an EHC plan – families should not have to re-enter the system as new entrants when their child is well enough to continue their education.

14. Inadequate transitions between settings (e.g. school to day service)

Not discussed.

Issues relating to Social Care

15. Children’s services stopped before adult services in place (esp. summer holidays)

Processes: Adjust processes to ensure compliance with the Care Act 2014, which requires local authorities to continue to provide a young person with children’s services until they reach a conclusion about their situation as an adult, so that there is no gap in provision.

Provision: There needs to be more provision for young people with learning difficulties over the summer, including transport to venues.

16. Problems with social care assessments

Parents often find that their SNIPS service is stopped when their young person turns 18, without any advance warning, and without anyone telling them that they need to request an assessment from adult social care.

Parents are not told about the need to request a carer's assessment, e.g. to help them stay in employment.

Parents are not aware of the different eligibility criteria used by children's and adult social care.

Parents feel that the Assessment Questionnaire (AQ) is too generic, and that assessors lack skills (e.g. in relation to young people with autism, communication difficulties), and that there is no whole-family approach.

Information/communication: Provide information about community care assessments and carer's assessments as part of the preparing for adulthood review meetings for those with EHC plans.

Identify young people who may be eligible for services from adult social care (e.g. those who receive services from children's social care and those on the Case Register) and write to them around the time of their 17th birthday.

Provide training for SENCOs to ensure they comply with their information duties under the Autism Strategy (duty inform young people with autism of their right to a community care assessment and their parents of the right to a carer's assessment).

Processes: Continue to provide a young person with children's services until the council reaches a conclusion about their situation as an adult, so that there is no gap in provision (requirement under the Care Act 2014).

17. No social care and health representatives at transition reviews (Y9 onwards)

Smother transitions could be achieved if social workers and health workers attended annual review meetings at school, but there isn't enough capacity to do that.

Provision: Increase service capacity to allow for this to happen.

18. Lack of support with Direct Payments

19. Lack of suitable day centres and respite provision for young people

Not discussed.

Issues related to Health

The following issues were not discussed at the meeting due to lack of time. They will be addressed at a separate meeting with Health representatives.

20. Lack of involvement of GPs

When young people are discharged from some children's services (e.g. Neurology), they come under the care of their GP. Since GPs usually have very little involvement in the care of young people with complex needs until that point, they have insufficient knowledge of their condition, and may not be aware of relevant specialist services.

21. Patient experience of transition varies from service to service

Transitions from children's to adult health services are done by specialities, at different times, and patients have very different experiences.

22. Gap in health services for 16-18 year olds

23. Problems with emergency admissions to adult hospital

When a young person over the age of 16 requires an emergency admission, they can no longer go to the Children's Hospital. Staying on an adult ward can be very difficult for young people with learning difficulties. Problems include:

- parents not allowed to stay on the ward overnight
- hospital staff refusing to place the young person in a side room if they can't cope with being on a ward
- security issues, e.g. young person could leave the ward unnoticed
- issues around consent to medical treatment (application of Mental Capacity Act)
- staff not trained to communicate with people with learning difficulties

24. Change in focus from diagnosis to management; fewer appointments with consultant

Information: Advise parents of children without diagnosis to use the time at Ryegate well. If diagnosis would benefit the child, work hard to get tests/assessments/reports done BEFORE the child moves to adult health services.

Actions:

The following actions were agreed:

- Dee to take this report to a meeting of representatives from children's and adult Health, Education and Social Care

- SPCF to arrange a meeting with Sheffield College to discuss issues raised in this report
- SPCF to arrange a meeting with Health representatives to discuss issues raised in this report
- Dee to write a short paragraph outlining who parents should contact about transitions, while teams are being restructured, to be published via SPCF and the Local Offer
- Eva to send Dee examples of transition booklets developed by other local authorities
- SPCF and Mencap look at putting in a joint bid for transition support