
Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

APPENDICES

Working paper no: DH 2525a
February 2013

Department of Health Policy Research Programme

Project reference no. 016 0108

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ISBN 978-1-907265-21-1

A CIP catalogue record for this report is available from the British Library.

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Appendix A

Interview schedule for researching potential research sites

ASC Transition Study

Set up meeting with key contact in each case study site

Schedule for 'new' case study sites

1. Briefly introduce the study (go into detail later in meeting):

Introduce the aims/objectives of the new study

2. Clarification of the Service

- Is there a specialist ASC team in adult services?
 - If yes, who leads this?
 - If no, which team or manager has responsibility for assessing and meeting the needs of adults with ASC?

- **Is there a multi-agency transition service for young people with ASC:**

- ***If YES: Is this a generic transition service for all disabled young people who meet the criteria for the service or is it ASC-specific?***

1. *If a generic transition service for all disabled young people who meet the criteria for the service, ask:*

- 1.1 *What are the eligibility criteria for this service?*
 - 1.1.1 *Does this service include YP with ASC who also have a learning disability?*
 - 1.1.2 *Does it include YP with ASC who do not also have a learning disability? Does it include YP with high functioning autism and Asperger's Syndrome? Does it include YP in mainstream school? Does it include YP both with and without statements?*
 - 1.1.3 *Is having a diagnosis of ASC essential for accessing the service? Is diagnosis a barrier?*

- 1.2 *What is the structure of this service?*
 - 1.2.1 *Is there a dedicated team (role and structure of team)?*
 - 1.2.2 *Are there key workers in the team? If yes, who do the key workers work with, e.g. both those with and without statements?)*

- 1.3 *Brief overview of the transition service - What does the service entail?*

- 1.4 *What, if any, involvement do health, social care, Connexions, education, therapies, CAMHS, children's and adults services, etc have? What is the role of each?*
- 1.5 *What are the key agencies involved in supporting YP with ASC?*
- 1.6 *How is support from the different agencies coordinated, if indeed it is coordinated?*
- 1.7 *What numbers of YP are supported by this service?*
 - 1.7.1 *What numbers of YP with ASC are supported by this service?*
 - 1.7.2 *Do you know how many children with ASC there are in your area?*
- 1.8 *How early does the transition service get involved?*
 - 1.8.1 *How early do adult services become involved?*
 - 1.8.2 *At what age do YP enter and exit the service? Does this differ between different agencies?*
 - 1.8.3 *How does the service define 'completion' of transition'?*
- 1.9 *Is there a steering group for the service? Which agencies are on the steering group? What is the level of seniority of those on the steering group?*
- 1.10 *Which YP with ASC does the service not support? Who supports them? Ask if there is an ASC-specific service then follow the questions below. If no ASC-specific service, ask if there is anything at all to support YP with ASC at transition.*

2. *If an ASC-specific service:*

- 2.1 *What are the eligibility criteria for this service?*
 - 2.1.1 *Does this service include YP with ASC who also have a learning disability?*
 - 2.1.2 *Does it include YP with ASC who do not also have a learning disability? Does it include YP with high functioning autism and Asperger's Syndrome? Does it include YP in mainstream school? Does it include YP both with and without statements?*
 - 2.1.3 *Is having a diagnosis of ASC essential for accessing the service? Is diagnosis a barrier?*
- 2.2 *What is the structure of this service?*
 - 2.2.1 *Is there a dedicated team (role and structure of team)?*
 - 2.2.2 *Are there key workers in the team? If yes, who do the key workers work with, e.g. both those with and without statements?)*

- 2.3 *What does the service entail?*
- 2.4 *What are the key agencies involved in supporting YP with ASC?*
- 2.5 *What, if any, involvement do health, social care, Connexions, education, therapies, CAMHS, children's and adults services, etc have? What is the role of each?*
- 2.6 *How is support from the different agencies coordinated, if indeed it is coordinated?*
- 2.7 *How, if at all, does this service link in with the generic multi-agency transition service?*
- 2.8 *What numbers of YP with ASC are supported by this service?*
 - 2.8.1 *Do you know how many children with ASC there are in your area?*
- 2.9 *How early does the transition service get involved?*
 - 2.9.1 *How early do adult services become involved?*
 - 2.9.2 *At what age do YP enter and exit the service? Does this differ between different agencies?*
 - 2.9.3 *How does the service define 'completion' of transition'?*
- 2.10 *Is there a steering group for the service? Which agencies are on the steering group? What is the level of seniority of those on the steering group?*
- 2.11 *Which YP with ASC does the service not support? Who supports them?*

3 *If NO, is there any form of transition service for young people with ASC?*

If YES:

- 3.1 *What are the eligibility criteria for this service?*
 - 3.1.1 *Does this service include YP with ASC who also have a learning disability?*
 - 3.1.2 *Does it include YP with ASC who do not also have a learning disability? Does it include YP with high functioning autism and Asperger's Syndrome? Does it include YP in mainstream school? Does it include YP both with and without statements?*
 - 3.1.3 *Is having a diagnosis of ASC essential for accessing the service? Is diagnosis a barrier?*

- 3.2 *What is the structure of this service?*
 - 3.2.1 *Is there a dedicated team (role and structure of team)?*
 - 3.2.2 *Are there key workers in the team? If yes, who do the key workers work with, e.g. both those with and without statements?)*
- 3.3 *If any support is available, probe for details – eligibility, which agencies are involved, numbers of YP with ASC supported, what the service/support entails, age of entering and exiting the service.*
- 3.4 *What numbers of YP with ASC are supported by this service?*
 - 3.4.1 *Do you know how many children with ASC there are in your area?*
- 3.5 *Is there a steering group for such work? Which agencies are on the steering group? What is the level of seniority of those on the steering group?*
- 3.6 *How, if at all, does this service link in with the generic multi-agency transition service?*
- 3.7 *How early does the transition service get involved?*
 - 3.7.1 *How early do adult services become involved?*
 - 3.7.2 *At what age do YP enter and exit the service? Does this differ between different agencies?*
 - 3.7.3 *How does the service/support define 'completion' of transition'?*
- 3.8 *What happens to those who do not meet eligibility criteria? How are they supported?*

If NO:

- 3.9 *What happens to YP with ASC who do not have a learning disability and/or are in mainstream schools? How are they supported through transition? Are there any autism specific projects/services/support work?*

Ask of all:

- 4 *Do you use person-centred planning with young people with ASC? If so, with which young people (e.g. only those in special schools)?*
- 5 *What transition arrangements are in place for young people with ASC who are placed out of area?*

3. Explain the requirements of the study

3a. Interviews with staff

Explain that the bulk of the interviews could be undertaken by telephone, but face-to-face interviews will be available if the potential participants prefer. Approximately 10 staff interviews per site (maximum of 12).

Establish relevant staff for interview:

Key staff working directly with young people with ASC at transition (aiming for maximum of 8 per site) and their managers (aiming for maximum of 4 per site)?

Possibilities:

- Transition worker (with a remit for ASC if possible) or others who work with young people with ASC during transition
- Transition service manager
- CAMHS/adult mental health services
- Manager of the learning disability team in adult social care
- Manager of the Connexions service (and staff who provide support for young people with ASC)
- Chair of an autism specific steering group (if one exists)
- Chair of the generic multi-agency steering group
- Any schools/colleges with particular expertise in autism (both special and mainstream schools)
- Youth Justice Teams?
- Other key individuals?

Procedures for contacting them: need names, addresses, telephone numbers and email addresses for each.

Contact name of person re: financial information.

Timescale – week when we can interview

Geographically where should we base ourselves? Recommended hotels?

3b. Family Questionnaires

Procedure for administration, including the procedures for YP with ASC who are supported outside the multi-agency service e.g. through Connexions.

Need to send the questionnaires to all YP with ASC (including those who receive a service from the generic multi-agency transition service).

Timescale

Contact person for administering the survey (generic transition service and ASC specific service or Connexions/CAMHS)

No. of young people currently being supported

No of young people who have exited the transition service in the last two years

Level of disability of young people being supported (esp. in terms of questionnaire)

4. Partnership agreement

Happy with details in partnership agreement?

If so, both sign two copies and keep one each.

If not, discuss, reassure – bring any major issues back to CI.

Appendix B
Staff Recruitment Materials

B1 Staff covering letter email

Autism Transition Study - University of York

Dear

I am a Research Fellow from the University of York, conducting a piece of research into 'Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions (ASC)'. This Department of Health funded study focuses on transition for young people on the autistic spectrum - from those with severe learning difficulties to those with high-functioning autism and Asperger's Syndrome. Please see the attached summary information sheet for further details. This study is being supported in [name of site] by [name and position of lead person(s)].

As part of the study, I need to speak to managers and practitioners from those services and agencies working with young people with ASC during the transition period from child to adult services and within adulthood. Thus, I am inviting you to take part in a telephone interview in your role within [name of service] to discuss the work that you/your service undertake with young people with ASC during transition. I would also be interested in your views on what you feel are the gaps in service; barriers to support for young people with ASC at transition; and also focus on any good practice around young people with ASC at transition. The interview could take 45 minutes to an hour. Please note that confidentiality and anonymity are guaranteed.

If you are happy to take part in the study and can spare me up to an hour of your time I would be very grateful. If so, please could you email me directly at nem501@york.ac.uk as soon as possible and indicate which dates and times you would be available for interview in [month].

The study has been approved by the local research governance office for [name of site], the national research ethics service, and it also has the support of the association of directors of adult social services (ADASS) and the association of directors of children's services (ADCS).

Thank you for your support; I look forward to hearing from you.

Very best wishes

Nicola Moran

Dr Nicola Moran, Research Fellow
Social Policy Research Unit (SPRU), University of York, Heslington, York, YO10 5DD
Tel: 01904 321970; Fax: 01904 321953; <http://www.york.ac.uk/inst/spru>

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Winner of the Queen's Anniversary Prize for Further and Higher Education 2009

B2 Summary of the study

Transition to Adult Services and Adulthood for Young People With Autistic Spectrum Conditions: Summary

Funder: Department of Health

Duration: November 2009 to January 2012

Researchers: Nicola Moran (SPRU), Patricia Sloper (SPRU), Wendy Mitchell (SPRU), Linda Cusworth (SPRU), and Jennifer Beecham (PSSRU, University of Kent)

Background

There is some evidence from research that for many young people with Autistic Spectrum Conditions (ASC) the process of transition from child to adult services is problematic. Current policy developments and the growth of multi-agency working may lead to improvements in this situation. However, there is little research which can identify the components of models of good practice in transition services or the costs of such services. Further, there is little detailed research specifically on the transition experiences of young people with autistic spectrum conditions (ASC) and their families, or on the specific practices of transition services for such young people. This study will provide in-depth qualitative data on the support provided for young people with ASC and their families in five case study areas. This will include support provided by multi-agency transition services and the support provided for any young people with ASC who do not meet eligibility criteria for such services. It will explore managers', staff, parents' and young people's views on the processes and outcomes of transition planning and support. Quantitative data on parents' and young people's satisfaction with service support; met and unmet needs; services used; and perceptions of receiving coordinated support, will also enable comparison between different services and different groups of young people with ASC.

Aims of the project

- To investigate the roles of multi-agency transition services in relation to young people with ASC, and the arrangements that are in place for coordinating services for young people with and without learning disabilities.
- To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services.

- To explore the costs and outcomes for young people of the transition process.
- To identify aspects of good practice in this area of work – what works, how does it work?

Methods

The study will build on our previous study of multi-agency transition services for disabled young people in five case study areas and information from another small study we carried out last year on arrangements for transition for young people in out of area residential placements. The main sites for this study will be three of the case study areas from the previous study, all of which have multi-agency transition teams/workers, and two additional areas that have also set up a multi-agency transition service encompassing young people with ASC. The case studies will examine in depth the differing models of transition services in the five areas, assessing their costs, evaluating their effectiveness in meeting the needs of young people with ASC and their families, and identifying factors within the models contributing to greater or lesser effectiveness.

In these case study areas, interviews will be undertaken with managers and staff to explore the organisation and operation of transition services and staff views of the effectiveness of the services in supporting young people with ASC through transition.

The effectiveness of the services in providing coordinated care and in meeting young people's and parents' needs will be investigated through questionnaires to all young people with ASC and their parents who are receiving, or have received, transition services, focusing on amount of service use, satisfaction with the services, processes of care and met and unmet needs.

In order to explore views of the services in more depth, interviews will be carried out with a sub-sample of young people with ASC and their parents who are going through or who have been through the transition process.

Cost-related analyses will provide descriptive results on costs of such services.

Policy aims

There is little research which explores transition for young people with ASC to identify the components of good practice that are associated with more positive experiences for young people and their parents. The proposed research will address these issues in order to inform standards of good practice in services for young people with ASC and their families at transition.

Contact person for the project: Nicola Moran (nem501@york.ac.uk)

Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Information Leaflet for Staff

The purpose of this leaflet is to explain the research and what will happen if you decide to take part.

What is the research about?

There is some evidence from research that for many young people with autistic spectrum conditions the process of transition from child to adult services is problematic. Current policy developments and the growth of multi-agency working may lead to improvements in this situation. However, there is little research which can identify the components of models of good practice in transition services or the costs of such services. Further, there is little detailed research specifically on the transition experiences of young people with autistic spectrum conditions (ASC) and their families, or on the specific practices of transition services for such young people. This research will address both these issues in order to inform good practice in services for young people with ASC and their families at transition.

Aims of the project:

- To investigate the roles of multi-agency transition services in relation to young people with ASC, and the arrangements that are in place for coordinating services for young people with and without learning disabilities.
- To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services.
- To explore the costs and outcomes for young people of the transition process.
- To identify aspects of good practice in this area of work.

Who is undertaking the study and how is it funded?

The study is based at the Social Policy Research Unit (SPRU), University of York and is being conducted by Nicola Moran, Tricia Sloper, Linda Cusworth, Wendy Mitchell and Jennifer Beecham. It is funded by the Department of Health.

Why do you want me to take part?

Your area is one of five case study areas selected to represent different models of transition services. We will be seeking the views of professionals, parents and young people about the transition service, to assess the effectiveness of the service in meeting the needs of young people and their families. In your area we will be interviewing managers, practitioners, transition workers and other relevant staff within social care, health and education. By agreeing to help, we would be able to draw upon your expertise and knowledge of the transition service in your area.

What would I have to do?

If you agree to participate, we will arrange to meet you for an interview at a time and place convenient to you, or to interview you by telephone if that is more convenient for you. The interview would last for a maximum of one hour. In the interview we will ask you for your views on a variety of issues concerning transition for young people with ASC. For example, which agencies are involved in delivering the service; difficulties and successes encountered; funding and costs of the service; the roles of transition workers; what training and support they receive and any recommendations for good practice in transition services for young people with ASC. We would like to record the interviews, but we will seek your permission in advance. If you prefer not to be recorded, we will make notes.

Do I have to take part?

You do not have to take part. This is voluntary and if you decide not to become involved you do not have to give a reason. If you decide to take part and later change your mind, you can withdraw at anytime.

Confidentiality

All information which is collected during the course of the research will be kept strictly confidential in line with the Data Protection Act. Data will be kept in locked storage for five years from the end of the study and then destroyed. No-one taking part in the project will be identifiable in the project report or any other publication.

What will happen to the information?

We will write reports and articles on the findings of the research and make sure that they are distributed widely to people who provide services and people who work in government departments. When the study is completed you will receive a summary of the findings.

Who has reviewed the study?

The ethical conduct of this study had been approved by a group of independent people at the Research Ethics Committee in Bradford. It has also been approved by the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS).

What do I do next?

If you are willing to consider taking part in an interview, please fill in the attached response sheet and return it to us in the FREEPOST envelope provided. We will then contact you by email or telephone and will be very pleased to answer any questions you may have about the project. If you are happy to take part in the study, we will also arrange a convenient time to visit you or possibly arrange to carry out a telephone interview. We will ask you to sign a consent form prior to the interview.

If you have any questions

If you would like any further information on the research, please contact Nicola Moran (nem501@york.ac.uk) at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Tel: 01904 321950.

B4 Staff consent form

**Transition to Adult Services and Adulthood for Young People with
Autistic Spectrum Conditions**

Consent Form for Staff

Please tick:

I have read the project information leaflet and understand the purpose of the project and what is involved Yes No

I understand that the project is strictly confidential and I will not be named in any project reports. Yes No

I understand that participation is voluntary and that I can withdraw from the project at any time without giving a reason. Yes No

I am willing to be interviewed as part of this research. Yes No

I agree for my interview to be digitally recorded. Yes No

Name of participant:

Signature:

Name of researcher:

Signature of researcher:

Date:

Appendix C
Staff Fieldwork Instruments

C1 Staff topic guide for interview with managers

ASC Transition Study

Topic Guide for Senior Managers

Introduction

- Introduce self and study.
- Check information sheet received and ask if any questions.
- Explain this is a one off interview of about an hour.
- Ask if okay to record interview. Recordings will be transcribed, kept safe and then destroyed after 5 years.
- Confidentiality – explain how quotes are used and presented.
- Get consent form signed.

A. Individual Service (CAMHS, Connexions ...)

1. Could you briefly describe to me your position and day to day role?
And, specifically, what is your role in relation to transition?
2. Tell me about what this service offers to young people with ASC and their parents:
 - a) In general.
 - b) In relation to transition.
3. What is the structure of this service?
 - a) Is there a dedicated team working with young people with ASC (role and structure of team)?
 - b) Are there key workers in the team? If yes, who do the key workers work with, e.g. both those with and without statements?)
4. What are the eligibility criteria for this service?
 - a) Does this service include YP with ASC who also have a learning disability?
 - b) Does it include YP with ASC who do not also have a learning disability, for instance those with high-functioning autism or Asperger's Syndrome?
 - c) Does it include YP with ASC in mainstream school?

- d) Does it include YP with ASC both with and without statements?
 - e) Is having a diagnosis of ASC essential for accessing the service? Is diagnosis a barrier?
 - f) Has this eligibility criteria changed recently? (from what)
5. Which YP with ASC does the service not support? Who supports them?
6. How many young people with ASC who are placed out of [name of site] does your service support?
- a) What arrangements are made for services to stay in contact with young people with ASC in out of area placements and anticipate their needs when they reach adulthood?
 - b) How well do you think this service supports young people with ASC who are not in their home area?
 - c) What are the barriers to providing a good service for young people with ASC who are not in their home area? What facilitates a good service for these young people?
 - d) Does the service support any young people with ASC who are placed in [name of site] from another authority? How many?
 - e) Are there any particular institutions in your area that take young people with ASC from other areas?
 - f) If yes, which institutions? What issues arise for your service from this?
7. How would you describe the particular characteristics of young people with ASC?
8. What skills do you think people need to support young people with autistic spectrum conditions?
- a) What skills are needed to support young people with ASC's involvement in transition planning?
 - b) Do you think there are particular difficulties for young people with ASC at transition?
9. Does your service provide any training on working with people with autistic spectrum conditions?
- a) If yes, what does it cover? Who provides it? How useful do you think it is?
 - b) If no, what, if any, training would you like to see provided?
10. Do adult services insist on a new core assessment for young people with ASC who may be transitioning to adult services?

11. What independent providers are there in this area for people with ASC? What do they do?

B. Links with the multi-agency transition service for young people with ASC

12. To what extent is the young person's transition internal (e.g. CAMHS to adult mental health services) or coordinated through the transition team?

13. How did you hear about the multi-agency transition service?

a) Do you feel you have enough information about the multi-agency transition service or would you like more?

14. What involvement do you have with the multi-agency transition service?

15. What systems do you have for sharing information with the transition service?

16. In what ways do you think the service works well for young people with ASC?

a) Why do you think this is the case?

b) How is good practice embedded?

c) Are there any innovative links in this area (e.g. with independent providers)?

17. In what ways do you think the service does not work well for young people with ASC?

a) Why do you think this is the case?

b) What are the barriers to a good service?

c) What happens when the service does not work well?

18. Does your service have any links with Youth Justice? If yes, describe.

19. Does the service support young people with ASC who wish to go into higher education? If yes, what role does the service have?

20. What do you feel are the gaps in transition services and/or in adult services for young people with ASC? Who is missing out?

21. What happens about the transition process for those young people with ASC who are excluded from school or are home educated?

C. Strategic Management of the Transition Service

22. Are you a member of the transition steering group?

If NO move to next section.

If YES continue with questions in this section.

- a) How frequently are steering group meetings held?
 - b) How long do the meetings last?
 - c) How long does it take you to travel to and from the meetings?
 - d) How much time do you spend preparing for the meeting and/or following up action points after the meeting?
 - e) How would you describe the purpose of the steering group?
 - f) How would you describe the aims and philosophy of the transition service?
23. Are you involved in any other meetings or groups related to transition for young people with ASC (e.g. tracking meetings, panel meetings, transition sub-group)? IF SO:
- a) Please explain the purpose of these meetings.
 - b) Who attends those meetings?
 - c) How frequently are these meetings held?
 - d) How long do the meetings last?
 - e) How long does it take you to travel to and from the meetings?
 - f) How much time do you spend preparing for the meeting and/or following up action points after the meeting?
24. Are some agencies more involved/committed to the multi-agency transition service than others? – How does the service encourage everyone to work together? How does the service encourage each individual to take responsibility?
25. What have been the main barriers to establishing partnerships between agencies? How have these been overcome?
26. How would you describe the services relationship, liaison and communication with agencies not on steering group e.g.: schools, employers and housing?
27. How does the service link into other programmes/initiatives in your area concerning transition issues for young people with ASC?
28. What do you think are the key factors that have helped or hindered the development of a multi-agency transition service for young people with ASC?

29. Does the transition service have a role in driving change about what is available for people with ASC in adult services? If yes, which adult services? If no, is there anyone pushing for this?
30. How is the service funded, how was funding negotiated and how secure is it?
31. What are the arrangements for reviewing and monitoring the transition service?

D. User participation

32. How is information about the service provided to young people with ASC and their parents?
33. To what extent is there/has there been user participation in service development? How does the service access the views of young people with ASC? How is this information kept, collated and used (if at all)?
34. How do you find out what young people's aspirations are (for those with and without statements)?
 - a) What, if any, advocacy services are provided/used?
 - b) How does the service try to meet these aspirations?
35. In what ways does the service attempt to meet the priorities and aspirations of parents of young people with ASC?
 - a) How does the service deal with situations where the aspirations of the parents differ to those of the young people?
36. What support is offered to the families of young people with ASC in transition?
37. What strategies are in place for supporting young people's social lives and reducing isolation?

E. Commissioning

38. What is the commissioning process across agencies for young people with ASC? Is there joint commissioning?
39. Will 'World Class Commissioning' inform or influence what you are doing?

40. What, if anything, has been the impact of 'Aiming High' on the service?

F. The Future

41. What are the plans for the future of the transition service for young people with ASC?

42. Are there more children being diagnosed with an ASC and coming through the service?

a) If so, how do you envisage this will shape future services?

43. How do you think services for young people with ASC need to be improved at transition?

44. What implications do you think the Autism Act and the strategy for adults with autism will have for your service?

C2 Staff topic guide for interview with practitioners

ASC Transition Study

Topic Guide for Practitioners

Introduction

- Introduce self and study.
- Check information sheet received and ask if any questions.
- Explain this is a one off interview of about an hour.
- Ask if okay to record interview. Recordings will be transcribed, kept safe and then destroyed after 5 years.
- Confidentiality – explain how quotes are used and presented.
- Get consent form signed.

A. Context

1. General details about the school/college/Connexions/CAMHS etc – size, age range, geographical area served?
2. Could you briefly describe to me your position and day to day role?
 - a. And, specifically, what is your role in relation to transition for young people with an ASC?
3. Approximately how many of the young people you work with/at this school/ on your caseload have an ASC?
 - a. What proportion of your caseload is this?
 - b. What proportion, if any, of those are categorised as high-functioning ASC/Asperger's?
 - c. How many young people have statements?
 - d. How many of these young people are supported by the multi-agency transition service?
4. How many young people with ASC on average do you have in transition (leaving school, exiting the service, entering adult services) each year?
5. How would you describe the particular characteristics of young people with ASC?

B. The individual service (CAMHS, Connexions, etc)

6. In your role, what service or support do you offer to young people with ASC and their parents in transition?
7. Do you work with YP with ASC who also have learning disabilities, or those with high-functioning autism/Asperger's syndrome, or both? Which YP with ASC do you not support and why? Who supports them?
8. Do you support any young people with ASC in transition who are placed out of area?
 - a. If yes, how many?
 - b. Are these young people who are placed out of [name of site]? Are there any who are placed in [name of site] from another authority?
 - c. What do you think facilitates a good service for these young people?
9. What skills do you think practitioners need to support young people with autistic spectrum conditions?
 - a. What skills are needed to support the involvement of young people with an ASC in transition planning?
 - b. Do you think that there are particular difficulties for young people with ASC at transition?
10. Have you had any training on working with people with autistic spectrum conditions?
 - a. If yes, what did it cover? Who provided it? How useful was it?
 - b. If no, do you think you would have found such training useful?
11. In your experience, do adult services insist on a new core assessment for young people with ASC who may be transitioning to adult services?

C. Links with the multi-agency transition service for young people with ASC

12. What involvement do you have with the multi-agency transition service?
13. How do you share information with the transition service? Do you experience any difficulties with information sharing?
14. In what ways do you think the Transition Service works well for young people with ASC?
 - a. Why do you think this is the case?
 - b. How is good practice embedded?

15. In what ways do you think the Transition Service does not work well for young people with ASC?
 - a. Why do you think this is the case?
 - b. What are the barriers to a good service?
 - c. What happens when the service does not work well?
16. Do you support any young people with ASC who are or have been involved with the Youth Justice system? If yes, how many? How do you work with the YJ system?
17. Do you support or have you supported young people with ASC who wish to go into higher education? If yes, what is your role with these young people?
18. What do you feel are the gaps in transition services and/or in adult services for young people with an ASC (those with an LD and those who are high-functioning/have Asperger's Syndrome)? Who is missing out?
19. How do you support young people with an ASC in transition who are excluded from school or who are home educated?

D. User participation

20. How do you involve young people with an ASC in planning for their transition?
 - a. Does this differ between young people with ASC who have learning disabilities and those who don't?
 - b. Does it differ between young people with ASC who have statements and those who don't?
 - c. What are the barriers to actively involving young people with ASC?
 - d. What facilitates the involvement of young people with ASC?
21. How do you involve the parents of young people with an ASC in transition planning for their son/daughter?
 - a. Does this differ between young people with ASC who have learning disabilities and those who do not?
 - b. Does it differ between young people with ASC who have statements and those who do not?
 - c. What are the barriers to actively involving parents?
 - d. What facilitates parents' involvement?

22. How do you find out what young people's aspirations are (for those with and without statements)? What, if any, advocacy services are provided/used? (Query social life, housing, higher education)
23. In what ways do you try to meet these aspirations?
24. In what ways do you attempt to meet the priorities and aspirations of the parents of young people with an ASC?
 - a. How do you deal with situations where the aspirations of the parents differ to those of the young people?
25. What support, if any, do you offer to the families of young people with ASC?
26. How, if at all, do you help young people with ASC take responsibility for their own health needs?
27. Do you have any strategies for supporting the social lives of young people with an ASC and reducing isolation?
28. To what extent do you undertake Person Centred Planning with YP with ASC?
 - a. If you do use PCP, what do you think are the advantages and disadvantages?
 - b. How useful do you think PCP is for the young person and their parents?

E. The Future

29. In general, where/what do young people with ASC transfer to after leaving this service? Prompts: education, training, employment, nothing.
30. In your experience, do there appear to be more children being diagnosed with an ASC and coming through the service?
 - a. If so, how do you envisage this will shape your work and future services?
31. How do you think services for young people with ASC need to be improved at transition?

Appendix D
Family Survey: Pre-transition
Questionnaire Packs

D1 Exemplar covering letter for parents pre-transition

[On Letterheaded Paper]

Insert reference here

Name and address

SOCIAL POLICY RESEARCH UNIT
University of York
Heslington, York, YO10 5DD

Telephone: (01904) 321950

Fax: (01904) 321953

Website: www.york.ac.uk/inst/spru

Email: nem501@york.ac.uk
lsc501@york.ac.uk

November 2010

Dear Parent/Carer

Re: Transition Services for Young People with Autistic Spectrum Conditions – Research Project

We would like to invite you to take part in a research project by filling in the enclosed questionnaire. The area you live in has been chosen as one of five areas in England to take part in this research project which is explained in more detail in the enclosed information sheet.

We would also like to find out the views of young people, so we have enclosed three questionnaire packs for your son/daughter. We only need your son/daughter to complete one of these questionnaires – please choose the one you and your son/ daughter feel is the most appropriate. If your son/daughter does not want to, or is unable to take part, this is OK. We are still interested in your views.

The study is based at the Social Policy Research Unit at the University of York and is funded by the Department of Health.

By taking part you will help to inform service providers about your son or daughter's experience of transition services. The aim of the research is to provide information that can help to improve services for young people with Autistic Spectrum Conditions and their families during the transition to adult services.

If you would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

Thank you for your time.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

D2 Parent information sheet for questionnaire: pre-transition

Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Information Leaflet for Parents/Carers (pre-transition)

This leaflet explains the research project, why you have been sent a questionnaire and what will happen if you decide to take part.

What is the research about?

The aim of the research is to provide information that can help to improve services for young people with autistic spectrum conditions (ASC) and their families during transition to adult services. The main aims of the project are:

- To look at how different services in England organise and manage the assessment, planning and actual transfer of young people with ASC to adult services and to look at how these services affect young people and their families.
- To gather the views of young people with ASC and their parents/carers about transition services and to find out which aspects of the services work or do not work for them.
- To develop recommendations about how transition services should best be provided for young people with ASC.

Who is undertaking the study and how is it funded?

The study is based at the Social Policy Research Unit (SPRU), University of York and is being conducted by Nicola Moran, Linda Cusworth, Tricia Sloper, Wendy Mitchell and Jennifer Beecham. It is funded by the Department of Health.

Why am I being asked to take part?

The area you live in is one of five areas in the country taking part in this research. We are trying to find out what you feel about the transition services which are offered in your area. It is important that we hear the views of as many families as possible. We want to know about the experiences of parents of young people who are preparing for transition (age 14 and upwards) and also parents of young people who have made the transition to adult services in the last two years. Your service provider has agreed to help by passing this information and questionnaire on to anyone who receives or has received transitions services. By completing the questionnaire you will help to inform services providers about

your experience of transition and by doing this, we hope that in the future young people with ASC and their families will get better support during transition.

Do I have to fill in the questionnaire?

No, you do not have to fill in the questionnaire. If you decide not to take part that is OK, you do not have to give a reason, although it would be helpful if you did. If you want to take part but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that your family receive. If you do not want to fill in this questionnaire and do not want any further contact about the research, please fill in your name and the name of your son/daughter on the front of the questionnaire and return the blank questionnaire to us in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire.

What does the questionnaire ask?

The questionnaire asks about the type of transition service you are receiving before your son or daughter transfers to adult services, if this service meets your family's needs and how satisfied you are with the services. The aim of the questionnaire is to give us an idea of how the transition service works and if it meets your family's needs. It will take about 15-20 minutes to complete the questionnaire and mainly involves ticking boxes. If you would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

The questionnaire also asks whether you would be willing for us to contact you again. We are looking for a number of families in each area who would be willing to be interviewed to discuss in more detail their experiences of transition services. However, if you complete the questionnaire, it does not mean you have to take part in an interview. We will not contact you again unless you say you would like to consider taking part in an interview.

Your son/daughter's views

We would like to find out the views of young people as well, so we have also enclosed three questionnaire packs for your son/daughter. Each pack contains a covering letter, information sheet and questionnaire. We only need your son/daughter to complete one of these questionnaires – please choose the one you and your son/daughter feel is the most appropriate. If your son or daughter is willing and able to complete the questionnaire, we would be very grateful for his or her response. If she/he does not want to, or is unable to take part, this is OK. We are still interested in your views. Again, if they would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

Confidentiality

All information which is collected during the course of the research will be kept strictly confidential in line with the Data Protection Act. Data will be kept in locked storage for five years from the end of the study and then destroyed. No-one taking part in the project will

be identifiable in the project report or any other publication. Your name will be removed from the questionnaire so that all the information is anonymous. All names will be kept separately from the questionnaires. We will not tell anyone that you are taking part.

What will happen to the information?

When we have completed the research we will produce a report which describes what parents, young people and staff have told us. This will report on all five areas taking part in the project. The report will include recommendations about the best way to meet the needs of young people with ASC and their families at the time of transition. The report will be sent to the Department of Health who are funding the research. If you would like to receive a summary of the report please complete and return the enclosed summary reply slip.

Who has reviewed the study?

The ethical conduct of this study had been approved by a group of independent people at the Bradford Research Ethics Committee.

What happens next?

If you are willing to take part please complete the enclosed questionnaire and return it, with your son/daughter's questionnaire if appropriate, in the FREEPOST envelope provided. You do not need to use a stamp. If you have any questions about filling in the questionnaire, or you would like help filling in the questionnaire, please contact Nicola Moran or Linda Cusworth using the email address, postal address or telephone number below.

Further information

If you would like any further information on the research, please contact Nicola Moran (nem501@york.ac.uk) or Linda Cusworth (lsc501@york.ac.uk) at the Social Policy Research Unit, University of York, Heslington, York, YO10 5DD. Tel: 01904 321289.

THANK YOU FOR YOUR TIME

D3 Parent questionnaire: pre-transition

Site Code _____

Transition Services for Young People and their Families

Questionnaire for Parents/Carers

Pre Transition

This questionnaire asks about the type of transition service your son/daughter receives, if this service meets your family's needs and the impact of the service on factors such as family stress. The aim of the questionnaire is to give us an idea of how the transition service works for your family. It will take about 15-20 minutes to complete and mainly involves ticking boxes. There is also an opportunity to write additional comments if you would like to.

If you want to take part in this research but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that your family receive. If you have any questions at all or would like help filling in this questionnaire, please ring Nicola or Linda on 01904 321289, and we will call you back. If you would like to complete this questionnaire online, please email Linda on lsc501@york.ac.uk.

Your name: (please print) _____

Your son/daughter's name: (please print) _____

- Please tick this box if you **DO NOT** want to fill in this questionnaire and do not want any further contact about the research.

Please could you tell us your reason(s) for not completing the questionnaire by ticking the appropriate box(es) below:

- Not receiving support from services for my son/daughter's transition
- Haven't got time to fill in questionnaire
- Too soon to comment on service
- Can't remember the service
- Other (please specify) _____

Please could you fill in your name and the name of your son/daughter and return the blank questionnaire in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire. **Thank you.**

All the information you give us is confidential. Your name will be removed from the questionnaire so that all the information is anonymous. All names will be kept separately from the questionnaire.

Please complete this questionnaire by _____ and return it in the freepost envelope provided or send to the following address:

**Social Policy Research Unit
University of York
FREEPOST YO378
Heslington
York
YO10 1GY.**

We are very grateful for your support of this research.

Thank you.

Section A: Planning for transition

1. Does your son/daughter have a written transition plan?
 Yes No Don't know
2. Does your son/daughter have a copy of this transition plan?
 Yes No Don't know
3. How old was your son/daughter when services first started planning for their transition to adult services/adulthood? _____
4. How often is this planning reviewed? _____
5. Do you feel that your transition plans are reviewed regularly enough?
 Yes, regularly Not regularly enough Not reviewed

Section B: Co-ordinated approach to transition

6. Do you have one person to support you and your son/daughter through transition?
 Yes No (*please go to Q16*) Don't know (*please go to Q16*)
7. What is this person's job title?
 Transition worker Teacher
 Social worker Nurse
 Key worker Connexions worker
 Mental health professional Lead professional
 Don't know
 Other (*please specify*) _____
8. Approximately for how long have you had this support? _____ Months _____ Years
9. In an average 3 month period, approximately how often have you seen this person?

If **not at all**, when did you last see them? _____
10. Typically, how long do these visits last? _____

11. **Would you like to see this person**

- More often About the same Less often?

12. **In an average 3 month period, approximately how often have you spoken to this person over the phone?** _____

If **not at all**, when did you last speak them to them over the phone? _____

13. **Typically, how long do these contacts last?** _____

14. **Would you like to talk to this person**

- More often About the same Less often?

15. **Regarding contact with this person:**

a) Do they contact you regularly?

- Yes No Don't know

b) Do they usually leave it up to you to contact them?

- Yes No Don't know

16. **Concerning how your son/daughter's transition is co-ordinated, please tick the box that best shows how much help you have or need from services in the following areas:**

	<i>Help not needed (yet)</i>	<i>Getting enough help</i>	<i>Need help/need more help</i>
Someone to talk to about your son/daughter's transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone speaking on behalf of the family when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone looking at your needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone providing individual support for you (e.g. emotional and practical support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone co-ordinating your son/daughter's transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone helping you to find suitable services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Overall, how satisfied are you with the transition service you receive?
 Very satisfied Satisfied Not satisfied Not at all satisfied
18. Concerning your son/daughter's transition what do you need most help with from services? _____

19. How can the transition service help you with this? _____

Section C: About your son/daughter

20. Is your child: Male Female?
21. How old is your son/daughter? _____
22. Which best describes your son/daughter's ethnic origin?
 White Indian
 Black-Caribbean Pakistani
 Black African Bangladeshi
 Chinese Other (*please specify*) _____
23. Is your son/daughter either fostered or adopted?
 No Fostered Adopted
24. Please describe any diagnosis you have been given for your son/daughter's condition (e.g. autism, Asperger's syndrome, high functioning autism).

25. How old was your son/daughter when you were given this diagnosis?

26. Does your son/daughter have any other conditions (e.g. learning disability, ADHD, epilepsy?) _____

27. The autistic spectrum covers a range of abilities, often referred to as high and low functioning. Whilst we acknowledge that this is not acceptable to everyone, it would be helpful to have an idea where your son/daughter is on the spectrum.

How would you describe your son/daughter's level of functioning?

- Low Quite low Medium High Very high

28 Does/did your son/daughter have a statement of special educational needs?

- Yes No Don't know

29. What type of *secondary school* does/did your son/daughter attend?

- Mainstream class, no extra adult support
- Mainstream class with extra adult support
- Special needs class/unit in mainstream school
- Autism specific class/unit in mainstream school
- Special school
- Autism specific class/unit in special school
- Special school which specialises in autism/Asperger syndrome
- Residential school
- Other (*please specify*) _____

30. If your son/daughter is in *further or higher* education, what type of college do they attend?

- Not in **further or higher** education Residential college
- Further education college University
- Other (*please specify*) _____

31. If your son/daughter is no longer in *full-time* education, please indicate what they do during a typical week (*please tick all that apply for each day*):

	<i>Monday</i>	<i>Tuesday</i>	<i>Wednesday</i>	<i>Thursday</i>	<i>Friday</i>
Part-time education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stay at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid work (supported)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (<i>please specify</i>) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

32. Does your son/daughter have difficulties in any of the following areas:

	<i>Not at all</i>	<i>Some difficulties</i>	<i>A lot of difficulties</i>
Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety/worry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends/social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organising themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. Concerning your son/daughter's transition to adult services, please tick the box that best shows how much help your son/daughter has or needs from services in the following areas:

	<i>Help not needed (yet)</i>	<i>Getting enough help</i>	<i>Need help/need more help</i>
Communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioural difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career/employment opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure/social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independent living skills (e.g. managing money, safety, risk, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits/finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport/getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short breaks/respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adult relationships/sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes as your son/daughter grows up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare your son/daughter for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<i>Help not needed (yet)</i>	<i>Getting enough help</i>	<i>Need help/need more help</i>
Someone speaking on behalf of your son/daughter when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for your son/daughter to express their views about what they want for their future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifying future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Achieving future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

34. Concerning their transition, what do you feel your son/daughter needs most help with from services?

35. How can the transition services help your son/daughter with this?

Section D: Contact with other services

36. Has your son/daughter seen any of the following professionals in the *last 3 months*? Please tick those which your son/daughter has seen and indicate approximately how many times they have seen them in the last three months:

- GP/Family Doctor Seen approx. _____ times in last three months
- Hospital Doctor Seen approx. _____ times in last three months
- Children’s Social Worker Seen approx. _____ times in last three months
- Adult’s Social Worker Seen approx. _____ times in last three months
- Physiotherapist Seen approx. _____ times in last three months
- Speech and Language Therapist Seen approx. _____ times in last three months
- Psychologist Seen approx. _____ times in last three months
- Psychiatrist Seen approx. _____ times in last three months
- Community Nurse Seen approx. _____ times in last three months
- Community Paediatrician Seen approx. _____ times in last three months
- Occupational Therapist Seen approx. _____ times in last three months
- Voluntary Worker Seen approx. _____ times in last three months
- School Nurse Seen approx. _____ times in last three months
- Connexions worker Seen approx. _____ times in last three months

37. How many times has your son/daughter visited accident and emergency in the last three months? _____
38. How many inpatient stays has your son/daughter had in last three months? _____
39. Does your son/daughter have short break services? Yes No
 If yes, how many days per month _____ or per year _____

Section E: Stress

40. Have your contacts with transition services affected the amount of stress you have experienced in caring for your son/daughter in the past six months? *(Please tick one box only)*
- Considerably reduced my stress Somewhat reduced my stress
 Not had any effect on my stress Somewhat increased my stress
 Considerably increased my stress
41. Concerning your son/daughter’s transition what, if anything, causes or caused you the most concern?

Section F: About you and your family

42. Are you the child’s
 Mother Father Other *(please specify)* _____
43. Are you ..?
 Married or living with a partner Separated or divorced
 Single Widowed

If you are married or living with a partner, please fill in the questions 44 to 48 about your partner as well as yourself.

44. Are you and/or your partner employed? (if neither you nor your partner are employed, please go to Q 49)

	You	Your partner
Yes - Full-Time	<input type="checkbox"/>	<input type="checkbox"/>
Yes - Part-Time	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>

45. Do you and/or your partner work as an employee or self-employed?

	You	Your partner
Employee	<input type="checkbox"/>	<input type="checkbox"/>
Self-employed with employees	<input type="checkbox"/>	<input type="checkbox"/>
Self-employed/freelance without employees	<input type="checkbox"/>	<input type="checkbox"/>

46. Which of the following best describes the sort of work that you and/or your partner do? (Please tick ONE box only for each of you)

	You	Your partner
Modern professional occupations Such as: teacher – nurse – physiotherapist – social worker – welfare officer – artist – musician – police officer – software designer	<input type="checkbox"/>	<input type="checkbox"/>
Clerical and intermediate occupations Such as: secretary – personal assistant – clerical worker – office clerk – call centre agent – nursing auxiliary – nursery nurse	<input type="checkbox"/>	<input type="checkbox"/>
Senior managers or administrators Such as: finance manager – chief executive	<input type="checkbox"/>	<input type="checkbox"/>
Technical and craft occupations Such as: motor mechanic – fitter – inspector – plumber – printer – tool maker – electrician – gardener – train driver	<input type="checkbox"/>	<input type="checkbox"/>
Semi-routine manual and service occupations Such as: postal worker – machine operative – security guard – caretaker – farm worker – catering assistant – receptionist – sales assistant	<input type="checkbox"/>	<input type="checkbox"/>
Routine manual and service occupations Such as: driver – cleaner – porter – packer – sewing machinist – messenger – labourer – waiter/waitress – bar staff	<input type="checkbox"/>	<input type="checkbox"/>
Middle or junior managers Such as: office manager – retail manager – bank manager – restaurant manager – warehouse manager – publican	<input type="checkbox"/>	<input type="checkbox"/>
Traditional professional occupations Such as: accountant – solicitor – medical practitioner – scientist – civil/mechanical engineer	<input type="checkbox"/>	<input type="checkbox"/>

47. How many people work for your employer and/or your partner's employer?

	<i>Your employer</i>	<i>Your partner's employer</i>
1 to 24	<input type="checkbox"/>	<input type="checkbox"/>
25 or more	<input type="checkbox"/>	<input type="checkbox"/>

48. Do you and/or your partner supervise any other employees?

	<i>You</i>	<i>Your partner</i>
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>

49. Is your main source of family income from paid employment or social security benefits?

- Paid employment Social security benefits Don't know

50. Have your caring responsibilities for your child affected your employment?

- No I had to give up work to care for child
 I cannot work as many hours as I like I have not progressed as far in my job
 My employment has been affected in other ways (please specify)

51. If employed in the last 3 months, how many days have you had to miss work because of your caring responsibilities for your son/daughter? _____

Section G: Further research

We may be asking some parents/carers and young people to take part in an interview to find out more details about their experience of transition. If you would be willing to be contacted about this and to discuss this further, please add your contact details. We may then contact you with more information at a later date. Please note this does not commit you to being interviewed.

Address: (please print) _____

Telephone number: _____

Email: _____

Section H: Additional comments

Please note any specific comments on the transition service or any improvements you would like to see in the space below.

Thank you for taking the time to fill in this questionnaire.

Please return your questionnaire in the freepost envelope provided.

D4 Request for information in alternative languages

THE UNIVERSITY of York



If you would like information in another language or format, please ask us

إذا أردت المعلومات بلغة أخرى أو بطريقة أخرى، نرجو أن تطلب ذلك منا.

Arabic

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

Bengali

如欲索取以另一語文印製或另一格式製作的資料，請與我們聯絡。

Cantonese

Si vous souhaitez des informations dans une autre langue ou sous un autre format, veuillez nous le demander.

French

જો તમને માહિતી બીજી ભાષા અથવા રચનામાં જોઈતી હોય તો, કૃપા કરી અમને વિનંતી કરો.

Gujarati

यदि आपको सूचना किसी अन्य भाषा या अन्य रूप में चाहिये तो कृपया हमसे कहे

Hindi

ئەگەر زانیاریت بە زمانیکی کە یا بە فۆرمیکی کە دەوی تکایە داوامان لی بکە

Kurdish

Jeżeli chcieliby Państwo uzyskać informacje w innym języku lub w innym formacie, prosimy dać nam znać.

Polish

ਜੇ ਇਹ ਜਾਣਕਾਰੀ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਜਾਂ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ ਚਾਹੀਦੀ, ਤਾਂ ਇਹ ਸਾਥੋਂ ਮੰਗ ਲਓ।

Punjabi

Dacă doriți informații în altă limbă sau alt format, vă rugăm să ne întrebați.

Romanian

Молимо вас да нам се обратите ако желите да добијете овај документ на неком другом језику.

Serbian

Haddii aad rabtid in warar lagugu siyo hab luuqadeed o kale, fadlan na soo waydiiso.

Somali

Kama utahitaji taarifa katika lugha nyingine au mtindo mwingine, tafadhali tuambie.

Swahili

தகவலை வேறொரு மொழி அல்லது வேறு வடிவத்தில் பெற விரும்பினால் தயவுசெய்து எம்மைக் கேட்கவும்.

Tamil

Türkçe bilgi almak istiyorsanız, bize başvurabilirsiniz.

Turkish

اگر آپ کو معلومات کسی دیگر زبان یا دیگر شکل میں درکار ہوں تو براۓ مہربانی ہم سے پوچھیے۔

Urdu

Contact Nicola Moran (nem501@york.ac.uk) or Linda Cusworth (lsc501@york.ac.uk) or telephone 01904 321289.

D5 Summary reply slip

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



Transition Services for Young People and their Families

Would you like to receive a summary of the research findings?

Yes

No

If **YES**, please fill in your contact details on this sheet and return with your questionnaire in the freepost envelope provided.

Name: _____

Address: _____

THANK YOU

Please return with your questionnaire in the freepost envelope provided.

D6 Exemplar covering letter for young people pre- and post-transition

[On Letterheaded Paper]

WM/TF

E-mail: @york.ac.uk

Insert date here

Dear

**Re: In Transition: Young People with Autistic Spectrum Conditions
Growing Up and Planning for the Future**



My name is Wendy and I work at the Social Policy Research Unit at the University of York on the 'In Transition: Young people with autistic spectrum conditions (ASC) growing up and planning for the future' study.

Last year you filled in a questionnaire about transition help and support. I've photocopied the front page of the questionnaire in case you've forgotten what it looked like. It's attached to the back of this letter. The aim of the research is to help improve services and support for young people with ASC and their families as they leave school or college, move to adult services and plan for the future.

I'm writing to you because you said you might like to help with the final part of the study. The final part involves interviewing young people and some of their parents. Interviews will ask young people about their ideas and experiences of transition. The interview will take about 60 minutes. You can tell me about your ideas by talking to me, writing things down or using pictures. You can choose. The (green) information sheet tells you more about the study.

Continued/...

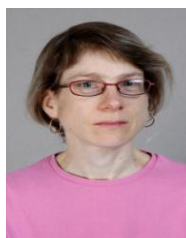
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In the next two or three weeks, I will ring you (or your parents) to tell you more about being interviewed. If you have any questions, you can ask me when I ring. If you say 'yes', I will arrange a day and time to come and talk to you.

You don't have to take part in the study, you can say 'no'. You don't have to give a reason but if you don't want to be interviewed, please can you let me know by ringing (01904 321950), emailing (wendy.mitchell@york.ac.uk) or writing to me (SPRU's address at the top of this letter).

Thanks for your help.

Best wishes



Wendy Mitchell

Enc

D7 Young person information sheet for questionnaire pre- and post-transition

THE UNIVERSITY *of York*

 spru | Social Policy
Research Unit



Transition Services for Young People Information Leaflet for Young People

This leaflet tells you about the transitions research project and why you have been sent a questionnaire.

Who are we?

We are researchers called Nicola Moran, Linda Cusworth, Tricia Sloper and Wendy Mitchell from the Social Policy Research Unit at the University of York. We are looking at transition from child to adult services for young people in England.

What is the research about?

The aim of the research is to find out more about what makes a good transition service for young people and what can be done to make transition to adult services better for young people. We would like to hear your views on transition. We would like to hear from young people who have not yet made the transition to adult services and from young people who have now transferred to adult services. What you tell us is important. The people who run transition services would like to know what young people think so that they can make transition better.

What do I have to do?

We would like you to fill in one of the three questionnaires about transition – you can choose which questionnaire to fill in. The questionnaire is short and mainly involves ticking boxes. If you would prefer to fill in the questionnaire online, please email Linda on lsc501@york.ac.uk.

Why me?

You live in an area which has been chosen to take part in the research. Your transition service is sending the questionnaires to all young people that they know so that we can hear the views of as many young people as possible.

Do I have to fill in the questionnaire?

No, you do not have to fill in the questionnaire. If you decide not to take part, that is OK, you do not have to give a reason, but it would be helpful if you did. However, please fill in your name on the front of one of the questionnaires and then return it in the envelope provided. We will then know not to contact you again. If you want to take part but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that you receive.

The questionnaire also asks whether you would be willing for us to contact you again to see if you would like to be interviewed to talk in more detail about your experiences of transition services. However, if you complete the questionnaire, it does not mean you have to take part in an interview. We will not contact you again unless you say you would like to be interviewed.

Will you tell anyone what I put in the questionnaire?

If you fill in the questionnaire, only the researchers will know your answers. Your answers will be kept private and we will not use your name in any report we write.

How will the information be used?

All the information from young people across the country will be put into a report. The report will suggest ways in which transition can be made better for young people. We will also send you a report if you want. We hope that the report will be used to help young people moving from children's to adult services in the future.

What happens next?

If you would like to take part please fill in one of the questionnaires and return it in the FREEPOST envelope. You do not need a stamp. If you have any questions about filling in the questionnaire, please contact Nicola Moran or Linda Cusworth by telephone on 01904 321289 or by email on nem501@york.ac.uk or lsc501@york.ac.uk

THANK YOU FOR YOUR TIME.

D8 Young person questionnaire pre-transition

Site code _____

THE UNIVERSITY *of York*



Transition Services for Young People Questionnaire for Young People

Pre Transition

Transition is the word used to describe leaving school and going to college, leaving children's services and going into adult services and when young people grow up and become adults.

We want to ask you what you think about this and whether you have enough help to prepare you for transition.

If you want to fill in this questionnaire but do not want to answer, or do not understand any questions, just leave them blank.

If you have any questions at all or would like help filling in this questionnaire, please ring Nicola or Linda on 01904 321289, and we will call you back.

If you would like to complete this questionnaire online, please email Linda on lsc501@york.ac.uk.

Your name: _____ Your age: _____

Please tick this box if you **DO NOT** want to fill in this questionnaire

Please could you tell us your reason(s) for not filling in the questionnaire by ticking the appropriate box(es) below:

I'm not receiving support from services for my transition

I haven't got time to fill in the questionnaire

I'm unable to fill in the questionnaire

Other (please specify) _____

Please could you fill in your name above and return the blank questionnaire in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire. **Thank you.**

Please send your completed questionnaire back by _____ in the freepost envelope provided, or send to the following address: **Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY**

THANK YOU VERY MUCH FOR YOUR HELP

1. Do you have one main person from services to support you in planning for transition?

Yes

No

Don't know

If you ticked **NO** or **DON'T KNOW**, please go to **Question 6**.

2. What is the name of this person?

3. What is this person's job?

4. Please tick YES or NO to tell us how this person helps you.

	YES	NO
They help me to think about what I want to do next	<input type="checkbox"/>	<input type="checkbox"/>
They give me advice and information	<input type="checkbox"/>	<input type="checkbox"/>
They ask for my ideas	<input type="checkbox"/>	<input type="checkbox"/>
They listen to me	<input type="checkbox"/>	<input type="checkbox"/>
They find things out for me	<input type="checkbox"/>	<input type="checkbox"/>
They visit me in school or college	<input type="checkbox"/>	<input type="checkbox"/>
They talk to me about how I feel	<input type="checkbox"/>	<input type="checkbox"/>

5. Would you like to see this person more often?

Yes

No

Don't know

6. Please tick the boxes to tell us about the help you have or need from services.

	Don't need help	Getting enough help	Need more help
Help with communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with self care (e.g. washing or dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with job or career opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with leisure or social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with independent living skills (e.g. shopping or cooking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with benefits or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with the transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with the transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transport or getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with short breaks or respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adult relationships or sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with emotional changes as you grow up (e.g. feeling sad or angry)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare you for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for you to say what you want for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with thinking about your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with achieving your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with getting information about transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please say)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>			

- 7. We may be asking some young people to take part in an interview where we would visit you and ask you more questions about your transition. If you would like to know more about this, please add your details below. We may then contact you with more information.**

Address: _____

Phone: _____

Email: _____

- 8. If you have any other comments about the help and support you are receiving during transition, please write them here.**

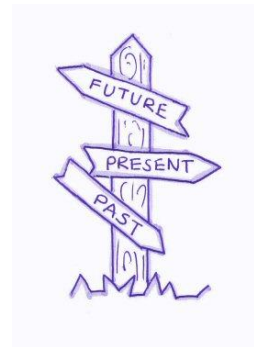
THANK YOU VERY MUCH FOR YOUR HELP

Please send your questionnaire back in the freepost envelope provided or send it to: Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY

D9 Young person short information sheet for questionnaire pre- and post-transition

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



Moving From Child to Adult Services

Information Leaflet for Young People

Can you help?

Hello! Our names are Nicola and Linda. We are researchers.

We are asking young people what they think about transition and moving from child to adult services.

We would like you to fill in one of the questionnaires about transition – you can choose which questionnaire to fill in. We would like to find out who has helped you to think about moving from child to adult services, and what help you have received from your transition service.

The questionnaire is very short and mainly involves ticking boxes. What you tell us is important. The people who run transition services would like to know what young people think so that they can make transition better. If you would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

You can choose

You do not have to fill in the questionnaire. If you decide not to take part that is OK. You do not have to give a reason, but it would be helpful if you did. If you want to take part but do not want to answer some of the questions, just leave them blank.

If you have any questions, you or your parent/carer can contact us by telephone on 01904 321289, or email at nem501@york.ac.uk (Nicola Moran) or lsc501@york.ac.uk (Linda Cusworth).

Thank you!

Nicola Moran and Linda Cusworth

D10 Young person short questionnaire pre-transition

Transition Services for Young People Young People's Questionnaire (Pre Transition)

Transition is the word used to describe leaving school and going to college, leaving children's services and going into adult services and when young people grow up and become adults.

We want to ask you what you think about this and whether you have enough help during transition.

Your name: _____

Your age: _____

1. Do you have one main person from services to support you in planning for transition?

Yes

No

Don't know

If you have ticked **NO** or **DON'T KNOW**, you do not need to answer any more questions. Please send the questionnaire back in the freepost envelope provided and thank you very much for your help.

2. What is the name of this person?
-

3. What is this person's job?

4. Please tick YES or NO to tell us how this person helps you.

	YES	NO
They help me to think about what I want to do next		
They give me advice and information		
They ask for my ideas		
They listen to me		
They find things out for me		
They visit me in school or college		
They talk to me about how I feel		

5. Would you like to see this person more often?

Yes

No

Don't know

Further help

We may be asking some young people to take part in an interview where we would visit you and ask you more questions about your transition. If you would like to know more about this, please add your address and phone number. We may then contact you with more information.

Address: _____

Phone: _____

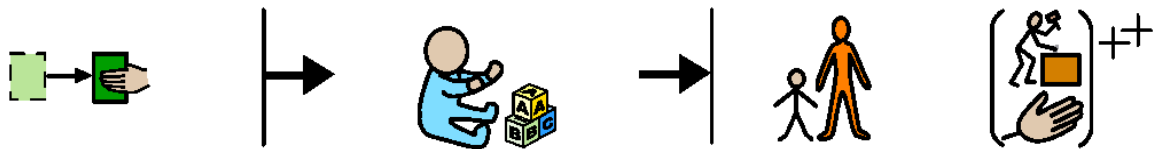
THANK YOU VERY MUCH FOR YOUR HELP

Please send your questionnaire back in the freepost envelope provided.

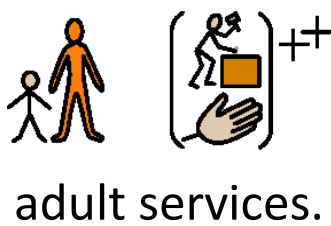
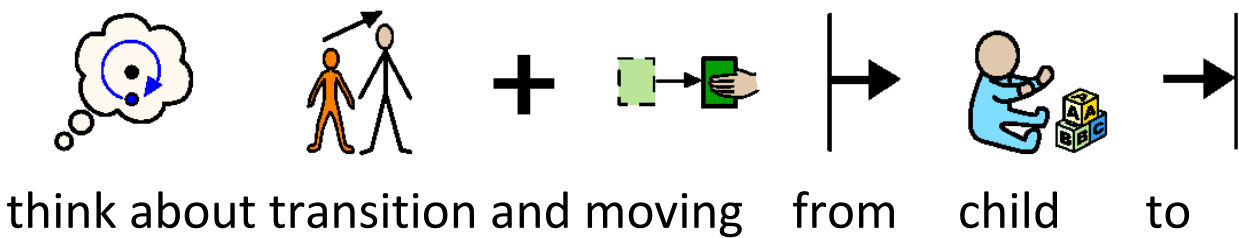
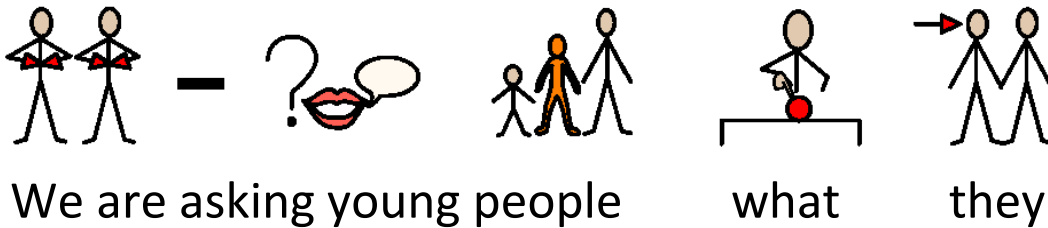
D11 Young person symbol information sheet for questionnaire pre-and post-transition



Information Leaflet



Moving from Child to Adult Services

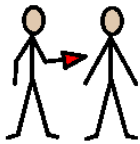




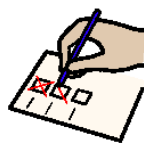
We



want



you



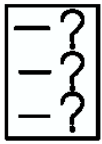
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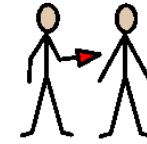
a



short



questionnaire about transition.



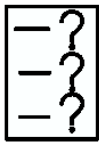
You do not have to



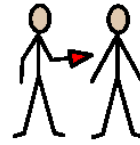
fill in



the questionnaire.



If



you



don't do it,



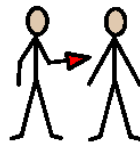
it



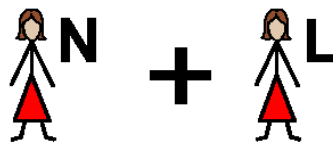
is



OK.



Thank you!



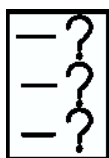
Nicola and Linda



Transition



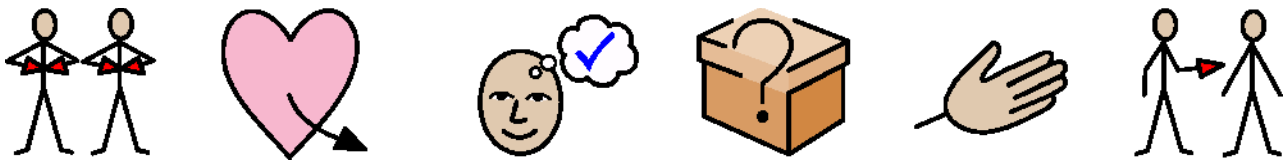
Project



Questionnaire



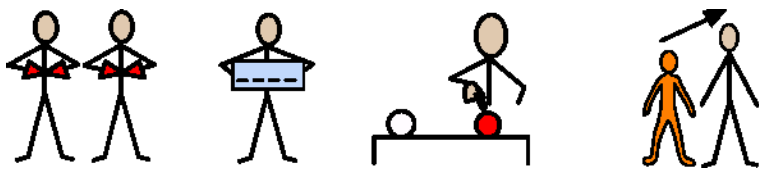
We are Nicola and Linda



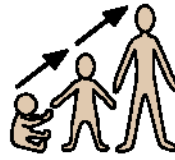
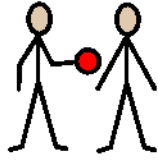
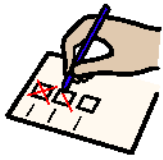
We want to know what help you



get moving from child to adult services.



We call this **transition**



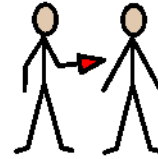
Please fill in

your name

and

age

and answer

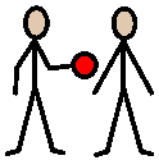


some questions for

us.

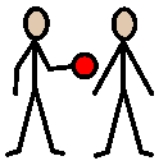
Thank

you!



Your name:

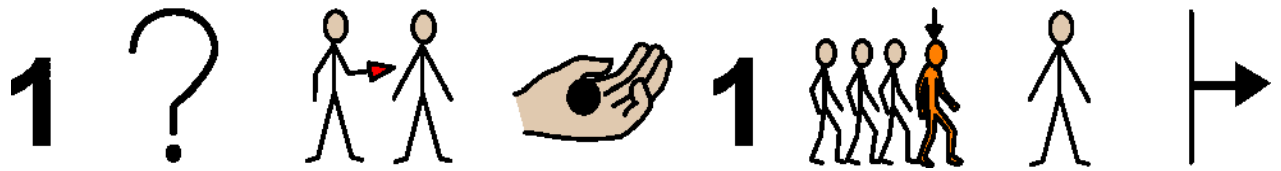
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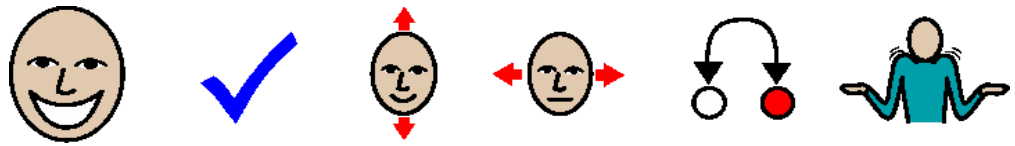
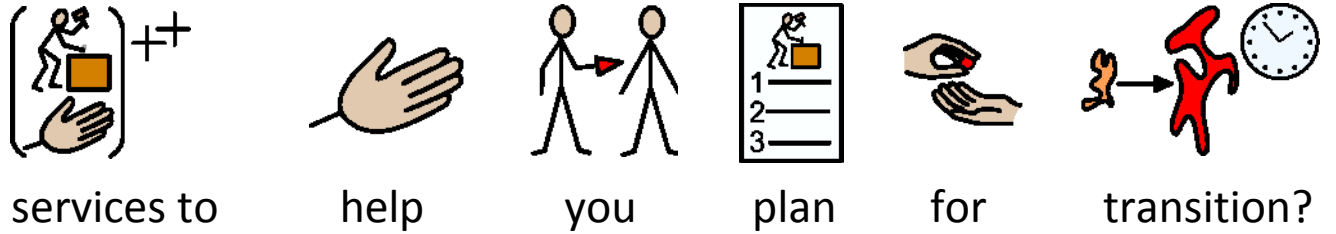
Your

age:

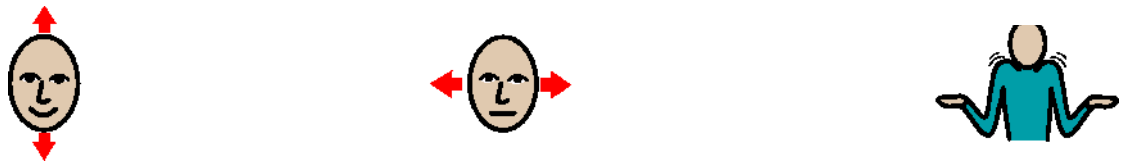
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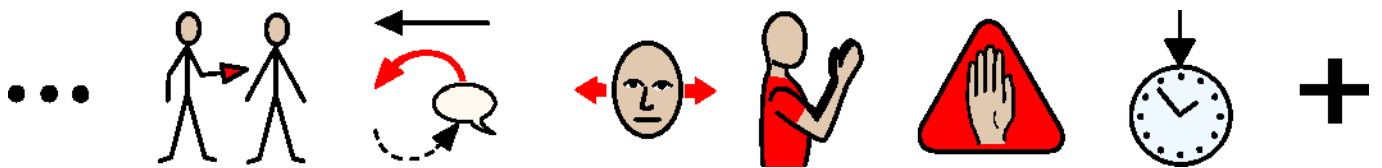
1 Do you have one main person from



Please tick yes, no or don't know









Yes No Don't know



If you answered NO, please stop now and









send this questionnaire back to us. Thanks.

2  -   >   

2 What is the name of the person who

helps you?

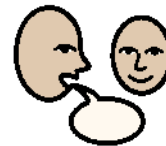
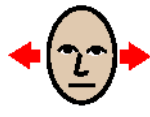
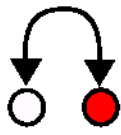
3  -   >   

3 What is the job of the person who

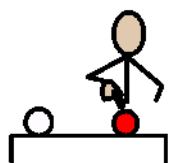
 

helps you?

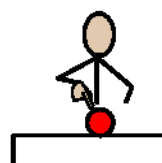
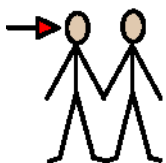
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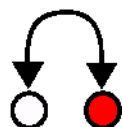
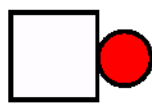
4. Please tick yes or no to tell



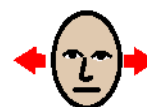
us how this person helps you...



They help me think about what I want



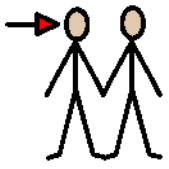
to do after school or college.



Yes

No

...



+



They

give

me

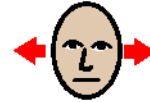
advice

and

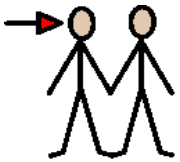
information



Yes



No



They

ask

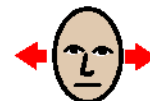
for

my

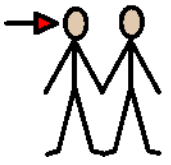
ideas



Yes



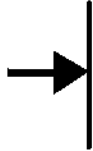
No



They



listen



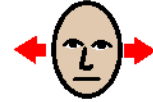
to



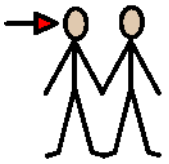
me.



Yes



No



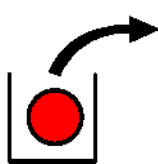
They



find



things



out



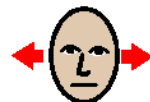
for



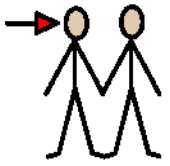
me.



Yes



No



They



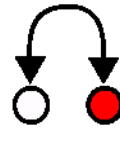
visit



me in



school



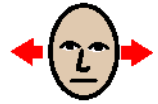
or



college.

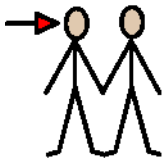


Yes

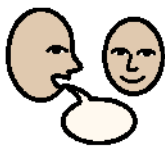


No

.....



They



talk to



me



about



how



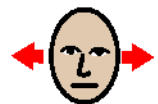
I





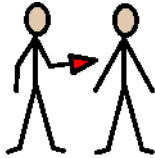


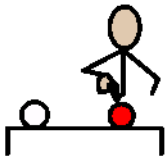

feel.




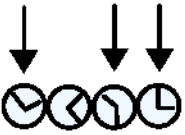
Yes






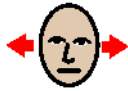


No


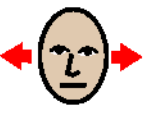

5 Would you like to see this person

more often?

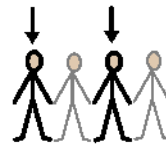
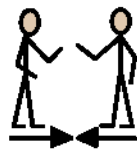
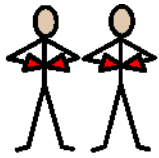







Please tick yes, no or don't know

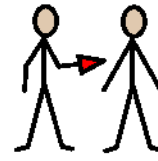




Yes No Don't know

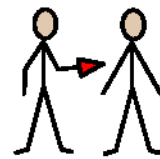
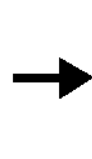
6



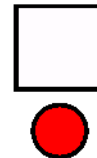
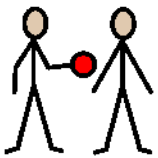
6. We may be meeting some young people to



talk about transition. If you would



like us to talk to you please fill in



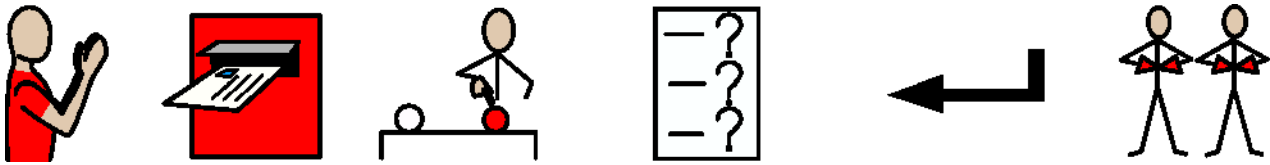
your address and phone number below.



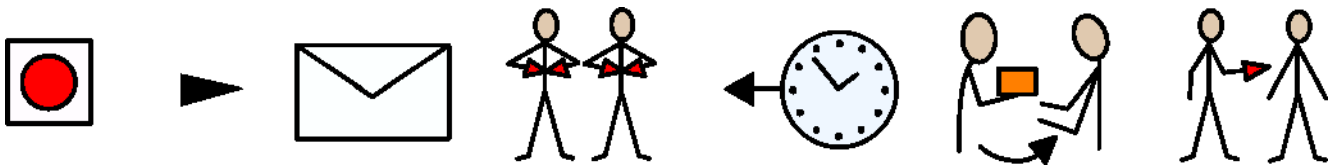
Address:



Phone number:



Please send this questionnaire back to us



in the envelope we have given you.



THANK YOU FOR YOUR HELP.

Appendix E
Family Survey: Young Person Post-transition
Questionnaire Packs

E1 Exemplar covering letter for young people pre- and post-transition

[On Letterheaded Paper]

NM/LC/TF

Email: nem501@york.ac.uk
lsc501@york.ac.uk

December 2010

Dear Young Person

Re: Transition Services for Young People – Research Project

Would you like to take part in a research project by filling in the enclosed questionnaire?

The area you live in has been chosen as one of five areas in England to take part in this project. The services that are helping, or have helped, you to prepare for transition from children's to adult services have sent these questionnaires to all young people that they know. You only need to complete one of these questionnaires – please choose the one that is best for you.

If you do not want to fill in this questionnaire and do not want any further contact about the research, please fill in just your name on the front of one of the questionnaires and return it to us in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire.

Continued/...

.../2

The information leaflet tells you all about the project. The aim of the research is to find out more about what makes a good transition service for young people and what can be done to make transition to adult services better. We would like to hear your views on this.

If you have any questions or would like help filling in this questionnaire, please ring Nicola or Linda on 01904 321289, and we will call you back. If you would prefer to fill in the questionnaire online please email Linda on lsc501@york.ac.uk

Thank you for your time.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

E2 Young person information sheet for questionnaire pre- and post-transition

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



Transition Services for Young People

Information Leaflet for Young People

This leaflet tells you about the transitions research project and why you have been sent a questionnaire.

Who are we?

We are researchers called Nicola Moran, Linda Cusworth, Tricia Sloper and Wendy Mitchell from the Social Policy Research Unit at the University of York. We are looking at transition from child to adult services for young people in England.

What is the research about?

The aim of the research is to find out more about what makes a good transition service for young people and what can be done to make transition to adult services better for young people. We would like to hear your views on transition. We would like to hear from young people who have not yet made the transition to adult services and from young people who have now transferred to adult services. What you tell us is important. The people who run transition services would like to know what young people think so that they can make transition better.

What do I have to do?

We would like you to fill in one of the three questionnaires about transition – you can choose which questionnaire to fill in. The questionnaire is short and

mainly involves ticking boxes. If you would prefer to fill in the questionnaire online, please email Linda on lsc501@york.ac.uk.

Why me?

You live in an area which has been chosen to take part in the research. Your transition service is sending the questionnaires to all young people that they know so that we can hear the views of as many young people as possible.

Do I have to fill in the questionnaire?

No, you do not have to fill in the questionnaire. If you decide not to take part, that is OK, you do not have to give a reason, but it would be helpful if you did. However, please fill in your name on the front of one of the questionnaires and then return it in the envelope provided. We will then know not to contact you again. If you want to take part but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that you receive.

The questionnaire also asks whether you would be willing for us to contact you again to see if you would like to be interviewed to talk in more detail about your experiences of transition services. However, if you complete the questionnaire, it does not mean you have to take part in an interview. We will not contact you again unless you say you would like to be interviewed.

Will you tell anyone what I put in the questionnaire?

If you fill in the questionnaire, only the researchers will know your answers. Your answers will be kept private and we will not use your name in any report we write.

How will the information be used?

All the information from young people across the country will be put into a report. The report will suggest ways in which transition can be made better for young people. We will also send you a report if you want. We hope that the report will be used to help young people moving from children's to adult services in the future.

What happens next?

If you would like to take part please fill in one of the questionnaires and return it in the FREEPOST envelope. You do not need a stamp. If you have any questions about filling in the questionnaire, please contact Nicola Moran or Linda Cusworth by telephone on 01904 321289 or by email on nem501@york.ac.uk or lsc501@york.ac.uk

THANK YOU FOR YOUR TIME

E3 Young person questionnaire post-transition

Site code _____



Transition Services for Young People Questionnaire for Young People

Post Transition

Transition is the word used to describe leaving school and going to college, leaving children's services and going into adult services and when young people grow up and become adults.

We want to ask you what you thought about this and whether you had enough help during transition.

If you want to fill in this questionnaire but do not want to answer or do not understand any questions, just leave them blank.

If you have any questions at all or would like help filling in this questionnaire, please ring Nicola or Linda on 01904 321289, and we will call you back.

If you would like to complete this questionnaire online, please email Linda on lsc501@york.ac.uk.

Your name: _____ Your age: _____

Please tick this box if you **DO NOT** want to fill in this questionnaire

Please could you tell us your reason(s) for not filling in the questionnaire by ticking the appropriate box(es) below:

I did not receive support from services for my transition

I haven't got time to fill in the questionnaire

I am unable to fill in the questionnaire

I can't remember the service

Other (please specify) _____

Please could you fill in your name above and return the blank questionnaire in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire. **Thank you.**

Please send your completed questionnaire back by _____ in the freepost envelope provided, or send to the following address: **Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY**

THANK YOU VERY MUCH FOR YOUR HELP

1. Did you have one main person from services to support you in planning for transition?

Yes

No

Don't know

If you ticked **NO** or **DON'T KNOW**,
please go to **Question 6**.

2. What was the name of this person?

3. What was this person's job?

4. Please tick YES or NO to tell us how this person helped you.

	<i>Yes</i>	<i>No</i>
They helped me to think about what I want to do next	<input type="checkbox"/>	<input type="checkbox"/>
They gave me advice and information	<input type="checkbox"/>	<input type="checkbox"/>
They asked for my ideas	<input type="checkbox"/>	<input type="checkbox"/>
They listened to me	<input type="checkbox"/>	<input type="checkbox"/>
They found things out for me	<input type="checkbox"/>	<input type="checkbox"/>
They visited me in school or college	<input type="checkbox"/>	<input type="checkbox"/>
They talked to me about how I was feeling	<input type="checkbox"/>	<input type="checkbox"/>

5. Would you have liked to see this person more often?

Yes

No

Don't know

6. This question is about the *past*. Please tick the boxes to tell us about the help you had or needed with your transition to adult services.

	<i>Did not need help</i>	<i>Got enough help</i>	<i>Needed more help</i>
Help with communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with self care (e.g. washing or dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with job or career opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with leisure or social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with independent living skills (e.g. shopping or cooking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with benefits or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with the transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transport or getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with short breaks or respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adult relationships or sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with emotional changes as you grow up (e.g. feeling sad or angry)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare you for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for you to say what you want for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with thinking about your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with achieving your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with getting information about transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please say) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. This question is about *now*. Please tick the boxes to tell us about the help you have or need from adult services.

	<i>Don't need help</i>	<i>Getting enough help</i>	<i>Need more help</i>
Help with communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with self care (e.g. washing or dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with job or career opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with leisure or social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with independent living skills (e.g. shopping or cooking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with benefits or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with the transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with transport or getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with short breaks or respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adult relationships or sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with emotional changes as you grow up (e.g. feeling sad or angry)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare you for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone speaking on your behalf when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for you to say what you want for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with thinking about your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with achieving your future goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please say) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. We may be asking some young people to take part in an interview where we would visit you and ask you more questions about your transition. If you would like to know more about this, please add your contact details. We may then contact you with more information.

Address: _____

Phone: _____

Email: _____

9. If you have any other comments about the transition service you received, please write them in the space below.

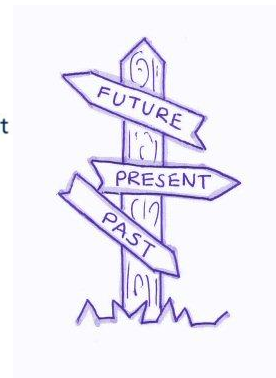
THANK YOU VERY MUCH FOR YOUR HELP

**Please send your questionnaire back in the freepost envelope provided or send it to:
Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY**

E4 Young person short information sheet for questionnaire pre- and post-transition

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



Moving From Child to Adult Services

Information Leaflet for Young People

Can you help?

Hello! Our names are Nicola and Linda. We are researchers.

We are asking young people what they think about transition and moving from child to adult services.

We would like you to fill in one of the questionnaires about transition – you can choose which questionnaire to fill in. We would like to find out who has helped you to think about moving from child to adult services, and what help you have received from your transition service.

The questionnaire is very short and mainly involves ticking boxes. What you tell us is important. The people who run transition services would like to know what young people think so that they can make transition better. If you would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

You can choose

You do not have to fill in the questionnaire. If you decide not to take part that is OK. You do not have to give a reason, but it would be helpful if you did. If you want to take part but do not want to answer some of the questions, just leave them blank.

If you have any questions, you or your parent/carer can contact us by telephone on 01904 321289, or email at nem501@york.ac.uk (Nicola Moran) or lsc501@york.ac.uk (Linda Cusworth).

Thank you!

Nicola Moran and Linda Cusworth

E5 Young person short questionnaire post-transition

Site code _____

THE UNIVERSITY *of York*

 spru | Social Policy
Research Unit

Transition Services for Young People Young People's Questionnaire (Post Transition)

Transition is the word used to describe leaving school and going to college, leaving children's services and going into adult services and when young people grow up and become adults.

We want to ask you what you thought about this and whether you had enough help during transition.

Your name: _____

Your age: _____

1. Did you have one main person from services to support you in planning for transition?

Yes

No

Don't know

If you have ticked **NO** or **DON'T KNOW**, you do not need to answer any more questions. Please send the questionnaire back in the freepost envelope provided and thank you very much for your help.

2. What was the name of this person?

3. What was this person's job?

4. Please tick YES or NO to tell us how this person helped you.

	YES	NO
They helped me to think about what I want to do next		
They gave me advice and information		
They asked for my ideas		
They listened to me		
They found things out for me		
They visited me in school or college		
They talked to me about how I felt		

5. Would you have liked to see this person more often?

Yes

No

Don't know

Further help

We may be asking some young people to take part in an interview where we would visit you and ask you more questions about your transition. If you would like to know more about this, please add your address and phone number. We may then contact you with more information.

Address: _____

Phone: _____

THANK YOU VERY MUCH FOR YOUR HELP

Please send your questionnaire back in the freepost envelope provided.



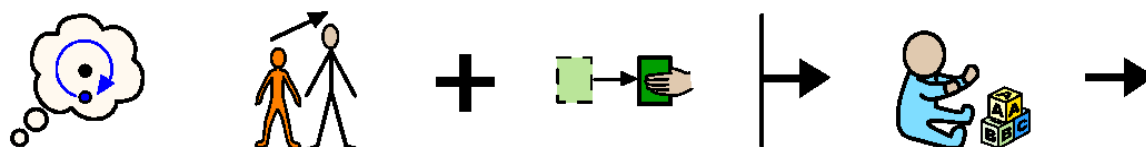
Information Leaflet



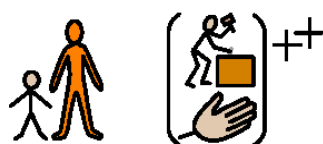
Moving from Child to Adult Services



We are asking young people what they



think about transition and moving from child to



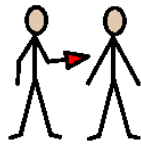
adult services.



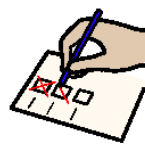
We



want



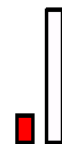
you



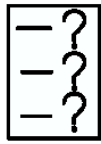
to fill in



a



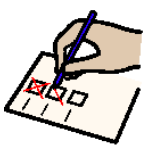
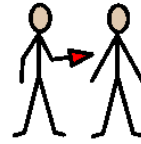
short



questionnaire about transition.



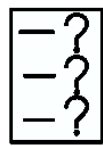
You do not have to



fill in



the questionnaire.



If



you



don't do it,



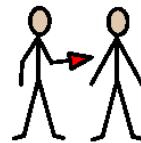
it



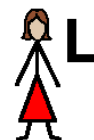
is



OK.



Thank you!



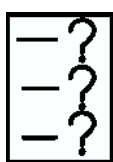
Nicola and Linda



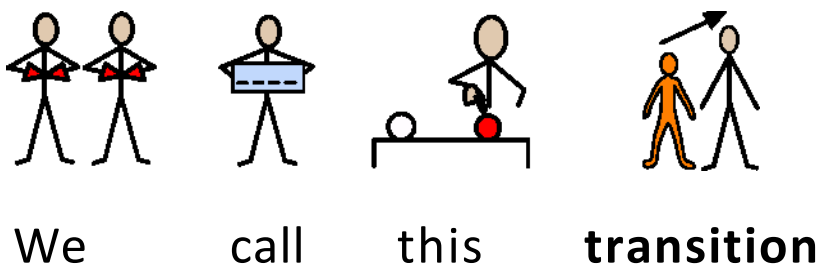
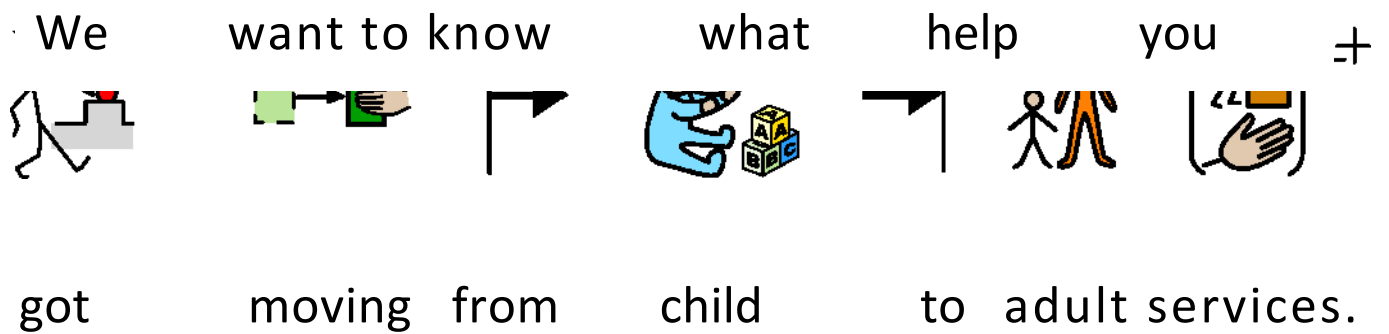
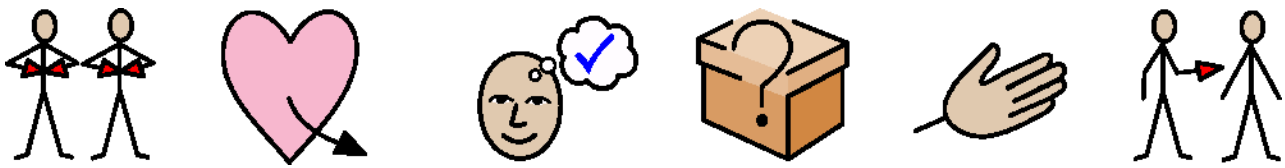
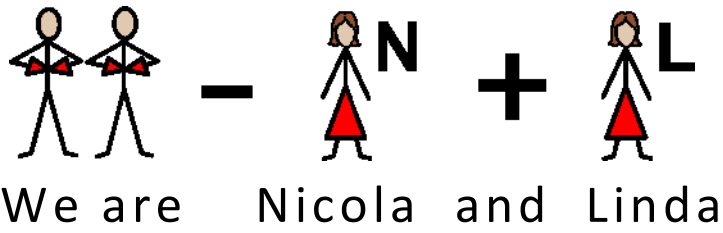
Transition

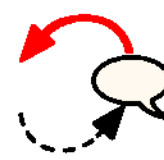
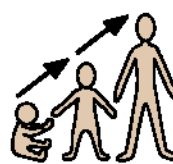
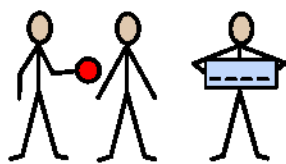
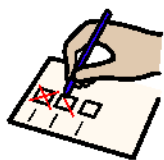


Project



Questionnaire





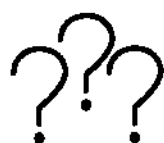
Please fill in

your name

and

age

and answer

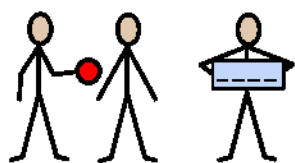


some questions for

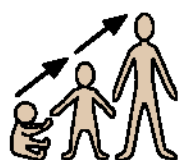
us.

Thank

you!



Your name:

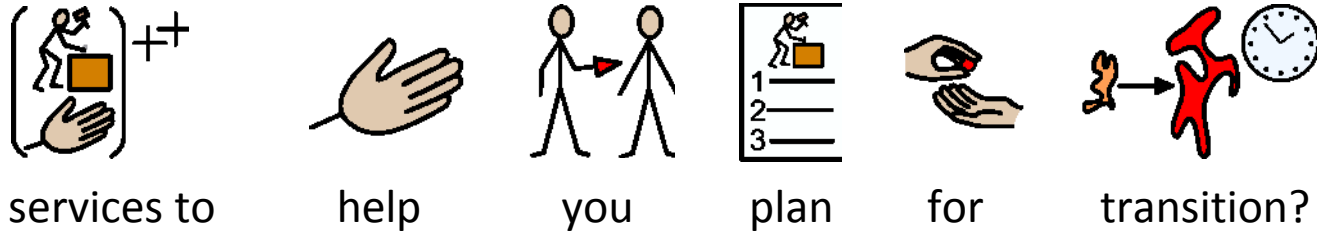


Your

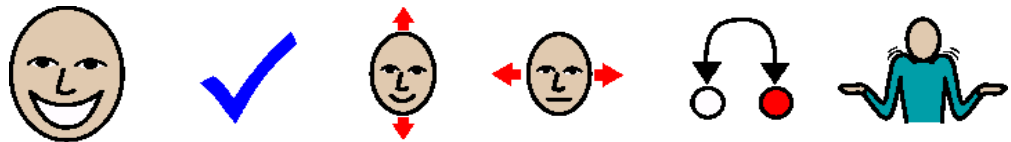
age:



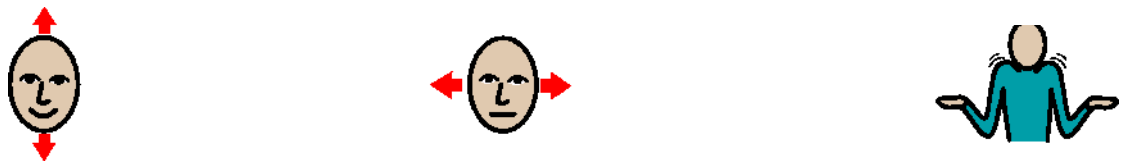
1. Did you have one main person from



services to help you plan for transition?



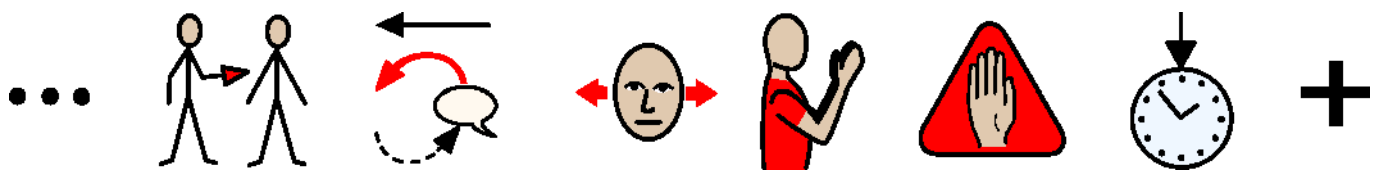
Please tick yes, no or don't know



Yes

No







Don't know



If you answered NO, please stop now and




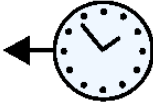




send this questionnaire back to us. Thanks.

2      

2 What was the name of the person who





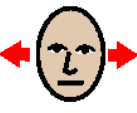
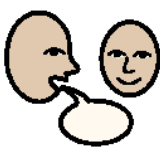
helped you?

3      



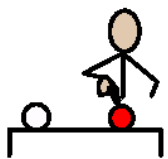

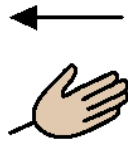
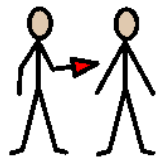
3 What was the job of the person who who

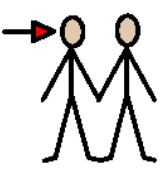
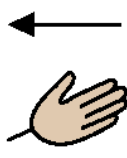


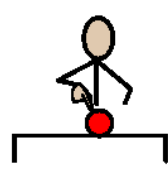

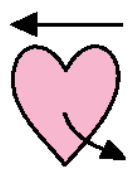
helped you?

4      


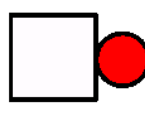



4. Please tick yes or no to tell

us how this person helped you...

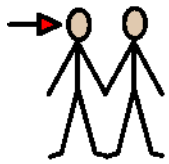
They helped me think about what I wanted

to do after school or college.

Yes No



They



gave



me



advice

+

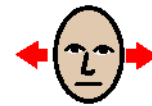
and



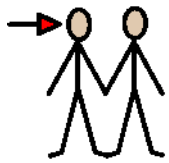
information



Yes



No



They



asked



for



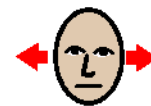
my



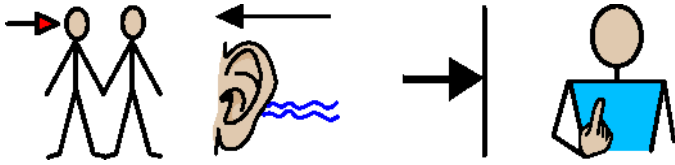
ideas



Yes



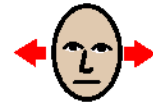
No



They listened to me.



Yes



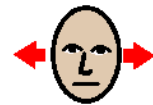
No



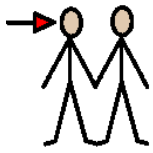
They found things out for me.



Yes



No



They

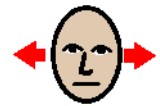
visited

me in

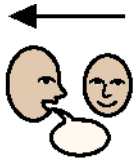
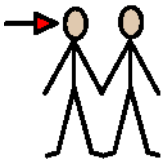
school

or

college.



Yes No



They

talked

to me

about

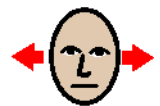
how

I

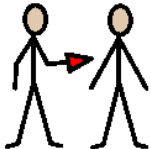


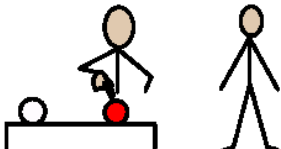
felt.




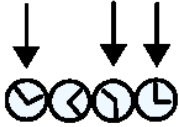
Yes






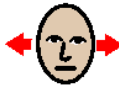
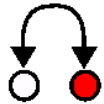

No

5 ?    

5. Would you liked to have seen this person


 

more often?

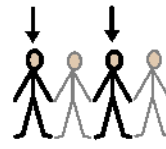
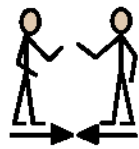
Please tick yes, no or don't know


Yes


No


Don't know

6



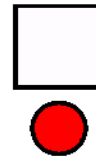
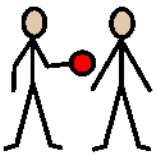
6 We may be meeting some young people to



talk about transition. If you would



like us to talk to you, please fill in



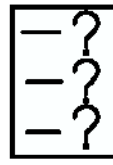
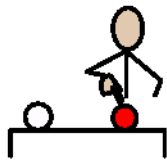
your address and phone number below.



Address:



Phone number:



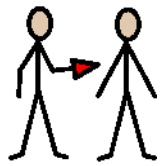
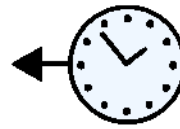
Please send

this

questionnaire

back to

us



in

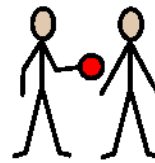
the envelope

we

have

given

you.



THANK YOU FOR YOUR HELP.

E8 Request for information in alternative languages

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



If you would like information in another language or format, please ask us

إذا أردت المعلومات بلغة أخرى أو بطريقة أخرى، نرجو أن تطلب ذلك منا.

Arabic

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

Bengali

如欲索取以另一語文印製或另一格式製作的資料，請與我們聯絡。

Cantonese

Si vous souhaitez des informations dans une autre langue ou sous un autre format, veuillez nous le demander.

French

જો તમને માહિતી બીજી ભાષા અથવા રચનામાં જોઈતી હોય તો, કૃપા કરી અમને વિનંતી કરો.

Gujarati

यदि आपको सूचना किसी अन्य भाषा या अन्य रूप में चाहिये तो कृपया हमसे कहे

Hindi

ئەگەر زانیاریت بە زمانیکی که یا بە فۆرمیکی که دەوی تکایە داوامان لێ بکە

Kurdish

Jeżeli chcieliby Państwo uzyskać informacje w innym języku lub w innym formacie, prosimy dać nam znać.

Polish

ਜੇ ਇਹ ਜਾਣਕਾਰੀ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਜਾਂ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ ਚਾਹੀਦੀ, ਤਾਂ ਇਹ ਸਾਥੋਂ ਮੰਗ ਲਓ।

Punjabi

Dacă doriți informații în altă limbă sau alt format, vă rugăm să ne întrebați.

Romanian

Молимо вас да нам се обратите ако желите да добијете овај документ на неком другом језику.

Serbian

Haddii aad rabtid in warar lagugu siyo hab luuqadeed o kale, fadlan na soo waydiiso.

Somali

Kama utahitaji taarifa katika lugha nyingine au mtindo mwingine, tafadhali tuambie.

Swahili

தகவலை வேறொரு மொழி அல்லது வேறு வடிவத்தில் பெற விரும்பினால் தயவுசெய்து எம்மைக் கேட்கவும்.

Tamil

Türkçe bilgi almak istiyorsanız, bize başvurabilirsiniz.

Turkish

اگر آپ کو معلومات کسی دیگر زبان یا دیگر شکل میں درکار ہوں تو براۓ مہربانی ہم سے پوچھیے۔

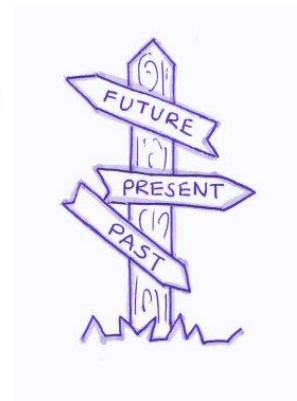
Urdu

Contact Nicola Moran (nem501@york.ac.uk) or Linda Cusworth (lsc501@york.ac.uk) or telephone 01904 321289.

E9 Summary reply slip

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spru | Social Policy
Research Unit



Transition Services for Young People and their Families

Would you like to receive a summary of the research findings?

Yes

No

If **YES**, please fill in your contact details on this sheet and return with your questionnaire in the freepost envelope provided.

Name: _____

Address: _____

THANK YOU

Please return with your questionnaire in the freepost envelope provided.

Appendix F
Family Survey: Parent Post-transition
Questionnaire Packs

F1 Exemplar covering letter for parents post-transition

[On Letterheaded Paper]

NM/LC/TF

Email: nem501@york.ac.uk
lsc501@york.ac.uk

December 2010

Dear Parent/Carer

Re: Transition Services for Young People with Autistic Spectrum Conditions – Research Project

We would like to invite you to take part in a research project by filling in the enclosed questionnaire. The area you live in has been chosen as one of five areas in England to take part in this research project which is explained in more detail in the enclosed information sheet.

The study is based at the Social Policy Research Unit at the University of York and is funded by the Department of Health.

By taking part you will help to inform service providers about your son or daughter's experience of transition services. The aim of the research is to provide information that can help to improve services for young people with Autistic Spectrum Conditions and their families during the transition to adult services.

If you would prefer to complete the questionnaire online, please email Linda Cusworth on lsc501@york.ac.uk

Thank you for your time.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

F2 Parent information sheet for questionnaire post-transition

Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Information Leaflet for Parents/Carers

This leaflet explains the research project, why you have been sent a questionnaire and what will happen if you decide to take part.

What is the research about?

The aim of the research is to provide information that can help to improve services for young people with autistic spectrum conditions (ASC) and their families during transition to adult services. The main aims of the project are:

- To look at how different services in England organise and manage the assessment, planning and actual transfer of young people with ASC to adult services and to look at how these services affect young people and their families.
- To gather the views of young people with ASC and their parents/carers about transition services and to find out which aspects of the services work or do not work for them.
- To develop recommendations about how transition services should best be provided for young people with ASC.

Who is undertaking the study and how is it funded?

The study is based at the Social Policy Research Unit (SPRU), University of York and is being conducted by Nicola Moran, Linda Cusworth, Tricia Sloper, Wendy Mitchell and Jennifer Beecham. It is funded by the Department of Health.

Why am I being asked to take part?

The area you live in is one of five areas in the country taking part in this research. We are trying to find out what you feel about the transition services which are offered in your area. It is important that we hear the views of as many families as possible. We want to know about the experiences of parents of young people who have made the transition to adult services in the last two years. Your service provider has agreed to help by passing this information and questionnaire on to anyone who has received transitions services. By completing the questionnaire you will help to inform services providers about your

experience of transition and by doing this, we hope that in the future young people with ASC and their families will get better support during transition.

Do I have to fill in the questionnaire?

No, you do not have to fill in the questionnaire. If you decide not to take part that is OK, you do not have to give a reason, although it would be helpful if you did. If you want to take part but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that your family receive. If you do not want to fill in this questionnaire and do not want any further contact about the research, please fill in your name and the name of your son/daughter on the front of the questionnaire and return the blank questionnaire to us in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire.

What does the questionnaire ask?

The questionnaire asks about the type of transition service you received before your son or daughter transferred to adult services, if this service met your family's needs and how satisfied you were with the services. The aim of the questionnaire is to give us an idea of how the transition service works and if it met your family's needs. It will take about 15-20 minutes to complete the questionnaire and mainly involves ticking boxes. If you would prefer to complete the questionnaire online, please email Linda Cusworth on lsc501@york.ac.uk

The questionnaire also asks whether you would be willing for us to contact you again. We are looking for a number of families in each area who would be willing to be interviewed to discuss in more detail their experiences of transition services. However, if you complete the questionnaire, it does not mean you have to take part in an interview. We will not contact you again unless you say you would like to consider taking part in an interview.

Confidentiality

All information which is collected during the course of the research will be kept strictly confidential in line with the Data Protection Act. Data will be kept in locked storage for five years from the end of the study and then destroyed. No-one taking part in the project will be identifiable in the project report or any other publication. Your name will be removed from the questionnaire so that all the information is anonymous. All names will be kept separately from the questionnaires. We will not tell anyone that you are taking part.

What will happen to the information?

When we have completed the research we will produce a report which describes what parents, young people and staff have told us. This will report on all five areas taking part in the project. The report will include recommendations about the best way to meet the needs of young people with ASC and their families at the time of transition. The report will be sent

to the Department of Health who are funding the research. If you would like to receive a summary of the report please complete and return the enclosed summary reply slip.

Who has reviewed the study?

The ethical conduct of this study had been approved by a group of independent people at the Bradford Research Ethics Committee.

What happens next?

If you are willing to take part please complete the enclosed questionnaire and return it in the FREEPOST envelope provided. You do not need to use a stamp. If you have any questions about filling in the questionnaire, or you would like help filling in the questionnaire, please contact Nicola Moran or Linda Cusworth using the email address, postal address or telephone number below.

Further information

If you would like any further information on the research, please contact Nicola Moran (nem501@york.ac.uk) or Linda Cusworth (lsc501@york.ac.uk) at the Social Policy Research Unit, University of York, Heslington, York, YO10 5DD. Tel: 01904 321289.

THANK YOU FOR YOUR TIME

F3 Parent questionnaire post-transition

Transition Services for Young People and their Families Questionnaire for Parents/Carers - Post Transition

This questionnaire asks about the type of transition service your son/daughter received before transferring to adult services, if this service met your family's needs and the impact of the service on factors such as family stress. The aim of the questionnaire is to give us an idea of how the transition service worked for your family. It will take about 20 minutes to complete and mainly involves ticking boxes. There is also an opportunity to write additional comments if you would like to.

If you want to take part in this research but do not want to answer some of the questions, just leave them blank. Whether or not you decide to take part will not affect any services that your family receive. If you have any questions at all or would like help filling in this questionnaire, please contact Nicola Moran or Linda Cusworth on 01904 321289, and we will call you back. If you would prefer to complete the questionnaire online, please email Linda on lsc501@york.ac.uk.

Your name: *(please print)* _____

Your son/daughter's name: *(please print)* _____

Please tick this box if you **DO NOT** want to fill in this questionnaire and do not want any further contact about the research,

Please could you tell us your reason(s) for not completing the questionnaire by ticking the appropriate box(es) below:

Did not receive support from services for my son/daughter's transition

Haven't got time to fill in questionnaire

Can't remember the service

Other (please specify) _____

Please could you fill in your name and the name of your son/daughter above and return the blank questionnaire in the freepost envelope provided. We will then know not to send you any reminders about the questionnaire. **Thank you.**

All the information you give us is confidential. Your name will be removed from the questionnaire so that all the information is anonymous. All names will be kept separately from the questionnaire.

Please complete this questionnaire by _____ and return it in the freepost envelope provided or send to the following address: **Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY.**

We are very grateful for your support of this research. Thank you.

Section A: Planning for transition

1. Did your son/daughter have a written transition plan?
 Yes No Don't know

2. Did your son/daughter have a copy of this transition plan?
 Yes No Don't know

3. How old was your son/daughter when services first started *planning* for their transition to adult services/adulthood? _____

4. How often was this planning reviewed? _____

5. Do you feel that your transition plans were reviewed regularly enough?
 Yes, regularly Not regularly enough Not reviewed

6. Did the transition plan specify services that your son/daughter should receive?
 Yes No
If Yes, has your son/daughter received these services? Yes No

Section B: Co-ordinated approach to transition

7. Did you have ONE person to support you and your son/daughter through transition?
 Yes No (*please go to Q.13*) Don't know (*please go to Q.13*)

8. **What was this person's job title?** *(please tick one box)*

- | | |
|--|---|
| <input type="checkbox"/> Transition worker | <input type="checkbox"/> Teacher |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Key worker | <input type="checkbox"/> Mental health professional |
| <input type="checkbox"/> Connexions worker | <input type="checkbox"/> Lead professional |
| <input type="checkbox"/> Don't know | |
| <input type="checkbox"/> Other <i>(please specify)</i> _____ | |

9. **Approximately how long did you have this support?** _____ months _____ years

10. **Would you have liked to have seen this person ...**

- More often About the same Less often?

11. **Would you have liked to have talked to this person ...**

- More often About the same Less often?

12. **Regarding contact with this person:**

a) Did they contact you regularly?

- Yes No Don't know

b) Did they usually leave it up to you to contact them?

- Yes No Don't know

13. Concerning how your son/daughter's transition was co-ordinated, please tick the box that best shows how much help you had or needed from services in the following areas.

	Help not needed	Got enough help	Needed help/needed more help
Someone to talk to about your son/daughter's transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone speaking on behalf of the family when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone looking at the needs of your son/daughter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone looking at your needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone providing individual support for you (e.g. emotional and practical support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone co-ordinating my son/daughter's transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone helping you to find suitable services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Overall, how satisfied were you with the transition services you received?

Very satisfied Satisfied Not satisfied Not at all satisfied

15. Concerning your son/daughter's transition what did YOU need most help with from services?

16. How could the transition services have helped you with this? _____

17. Overall, how well managed was the process of transferring between:

	Managed well	Managed OK	Poorly managed	Don't know	Not applicable
Children's and adult <u>social</u> care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's and adult <u>health</u> services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's and adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School to further education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School to day services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School to paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School to voluntary work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College to day services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College to paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College to voluntary work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (<i>please specify</i> _____)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C: About your son/daughter

18. Is your child ... Male Female?

19. How old is your son/daughter? _____

20. Which best describes your son/daughter's ethnic origin?

- | | |
|--|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Black-Caribbean | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Black African | <input type="checkbox"/> Bangladeshi |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Other (<i>please specify</i>) _____ |

21. Is your son/daughter either fostered or adopted?

- No Fostered Adopted

22. Please describe any diagnosis you have been given for your son/daughter's condition (e.g. autism, Asperger's syndrome, high functioning autism).

23. How old was your son/daughter when you were given this diagnosis? _____

24. Does your son/daughter have any other conditions (e.g. learning disability, ADHD, epilepsy?) _____

25. The autistic spectrum covers a range of abilities, often referred to as high and low functioning. Whilst we acknowledge that this is not acceptable to everyone, it would be helpful to have an idea where your son/daughter is on the spectrum. How would you describe your son/daughter's level of functioning?

Low Quite low Medium High Very high

26. Did your son/daughter have a statement of special educational needs?

Yes No Don't know

27. What type of *secondary school* did your son/daughter attend?

- Mainstream class, no extra adult support
- Mainstream class with extra adult support
- Special needs class/unit in mainstream school
- Autism specific class/unit in mainstream school
- Special school
- Autism specific class/unit in special school
- Special school which specialises in autism/Asperger syndrome
- Residential school
- Other (*please specify*) _____

28. If your son/daughter is still in *full-time education*, what type of college do they attend?

- No longer in full-time education University
 Further education college Residential college
 Other (*please specify*) _____

29. If your son/daughter is no longer in full-time education, please indicate what they do during a typical week (please tick all that apply for each day)

	Monday	Tuesday	Wednesday	Thursday	Friday
Part-time education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stay at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid Work (supported)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (<i>please specify</i>) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. Does your son/daughter have difficulties in any of the following areas ...

	Not at all	Some difficulties	A lot of difficulties
Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety/worry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends/social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organising themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. This question is about *the past*. Concerning your son/daughter's transition to adult services, please tick the box that best shows how much help YOUR SON/DAUGHTER had or needed from services in the following areas:

	Help not needed	Got enough help	Needed help/needed more help
Communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioural difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career/Employment opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure/social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independent living skills (e.g. managing money, safety, risk etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits/Finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport/getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short breaks/respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adult relationships/sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes as your son/daughter grows up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare your son/daughter for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone speaking on behalf of your son/daughter when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for your son/daughter to express their views about what they want for their future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifying future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Achieving future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (<i>please specify</i>) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

32. Concerning their transition, what do you feel YOUR SON/DAUGHTER needed most help with from services?

33. How could the transition services have helped your son/daughter with this?

34. This question is about *now* your son/daughter is in adult services. Please tick the box that best shows how much help YOUR SON/DAUGHTER has or needs from services in the following areas.

	Help not needed (yet)	Getting enough help	Need help/need more help
Communication needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other equipment needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioural difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Further education/training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career/Employment opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure/social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independent living skills (e.g. managing money, safety, risk etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits/Finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transfer to adult mental health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport/getting around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short breaks/respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adult relationships/sex education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes as your son/daughter grows up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support to prepare your son/daughter for the changes ahead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone speaking on behalf of your son/daughter when dealing with transition issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opportunities for your son/daughter to express their views about what they want for their future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifying future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Achieving future goals/aspirations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adapting to change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section D: Contact with other services

35. Is your son/daughter living at home with you at present?

Yes (If **YES**, please answer Questions 36 to 39)

No (If **NO**, please go to Section E Question 40)

36. Has your son/daughter seen any of the following professionals in the *last 3 months*? Please tick those which your son/daughter has seen and indicate approximately how many times have they seen them in the last three months:

- | | |
|---|---|
| <input type="checkbox"/> GP/Family Doctor | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Hospital Doctor | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Children's Social Worker | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Adult's Social Worker | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Physiotherapist | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Speech and Language Therapist | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Psychologist | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Psychiatrist | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Community Nurse | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Community Doctor (not GP) | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Occupational Therapist | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Voluntary Worker | Seen approx. _____ times in last three months |
| <input type="checkbox"/> College Nurse | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Connexions worker | Seen approx. _____ times in last three months |
| <input type="checkbox"/> Any other services
(please specify) | Seen approx. _____ times in last three months |
-

37. How many times has your son/daughter visited accident and emergency in the last three months? _____

38. How many inpatient stays has your son/daughter had in last three months? _____

39. Does your son/daughter have short break services? Yes No

If **YES**, how many days per month _____ or per year _____

Section E: Stress

40. Did your contacts with the transition service affect the amount of stress you experienced in caring for your son/daughter during the transition process?

(Please tick one box only)

Considerably reduced my stress

Somewhat reduced my stress

Not had any effect on my stress

Somewhat increased my stress

Considerably increased my stress

41. Concerning your son/daughter's transition what, if anything, caused you the most concern?

Section F: About you and your family

42. Are you the child's ...

Mother

Father

Other *(please specify)*

43. Are you?

Married or living as married Single Separated or divorced Widowed

If you are married or living with a partner, please fill in the questions 44 to 48 about your partner as well as yourself.

44. Are you and/or your partner employed? *(if neither you nor your partner are employed, please go to Q.49)*

	You	Your partner
Yes - Full-Time	<input type="checkbox"/>	<input type="checkbox"/>
Yes - Part-Time	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>

45. Do you and/or your partner work as an employee or self-employed?

	You	Your partner
Employee	<input type="checkbox"/>	<input type="checkbox"/>
Self-employed with employees	<input type="checkbox"/>	<input type="checkbox"/>
Self-employed/freelance without employees	<input type="checkbox"/>	<input type="checkbox"/>

46. Which of the following best describes the sort of work that you and/or your partner do? *(Please tick ONE box only for each of you)*

	You	Your partner
Modern professional occupations <i>Such as:</i> teacher – nurse – physiotherapist – social worker – welfare officer – artist – musician – police officer – software designer	<input type="checkbox"/>	<input type="checkbox"/>
Clerical and intermediate occupations <i>Such as:</i> secretary – personal assistant – clerical worker – office clerk – call centre agent – nursing auxiliary – nursery nurse	<input type="checkbox"/>	<input type="checkbox"/>
Senior managers or administrators <i>Such as:</i> finance manager – chief executive	<input type="checkbox"/>	<input type="checkbox"/>
Technical and craft occupations <i>Such as:</i> motor mechanic – fitter – inspector – plumber – printer – tool maker – electrician – gardener – train driver	<input type="checkbox"/>	<input type="checkbox"/>

Semi-routine manual and service occupations

Such as: postal worker – machine operative – security guard – caretaker – farm worker – catering assistant – receptionist – sales assistant

Routine manual and service occupations

Such as: driver – cleaner – porter – packer – sewing machinist – messenger – labourer – waiter/waitress – bar staff

Middle or junior managers

Such as: office manager – retail manager – bank manager – restaurant manager – warehouse manager – publican

Traditional professional occupations

Such as: accountant – solicitor – medical practitioner – scientist – civil/mechanical engineer

47. How many people work for your employer and/or your partner's employer?

	Your employer	Your partner's employer
1 to 24	<input type="checkbox"/>	<input type="checkbox"/>
25 or more	<input type="checkbox"/>	<input type="checkbox"/>

48. Do you and/or your partner supervise any other employees?

	You	Your partner
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>

49. Is your main source of family income from paid employment or social security benefits?

- Paid employment
- Social security benefits
- Don't know

50. Have your caring responsibilities for your child affected your employment?

- No
- I had to give up work to care for child
- I have not progressed as far in my job
- I cannot work as many hours as I like
- My employment has been affected in other ways (*please specify*) _____

51. If employed in the last 3 months, how many days have you had to miss work because of your caring responsibilities for your son/daughter? _____

Section G: Further research

We may be asking some parents/carers and young people to take part in an interview to find out more details about their experience of transition. If you would be willing to be contacted about this and to discuss this further, please add your contact details. We may then contact you with more information at a later date. Please note this does not commit you to being interviewed.

Address: _____

Telephone number: _____

Email: _____

Section H: Additional comments

Please note any specific comments on the transition service or any improvements you would like to see in the space below.

Thank you for taking the time to fill in this questionnaire.

Please return your questionnaire in the freepost envelope provided or send to the following address: **Social Policy Research Unit, University of York, FREEPOST YO378, Heslington, York YO10 1GY.**

F4 Request for information in alternative languages

THE UNIVERSITY of York

spru | Social Policy
Research Unit



If you would like information in another language or format, please ask us

إذا أردت المعلومات بلغة أخرى أو بطريقة أخرى، نرجو أن تطلب ذلك منا.

Arabic

যদি আপনি এই ডকুমেন্ট অন্য ভাষায় বা ফরমেটে চান, তাহলে দয়া করে আমাদেরকে বলুন।

Bengali

如欲索取以另一語文印製或另一格式製作的資料，請與我們聯絡。

Cantonese

Si vous souhaitez des informations dans une autre langue ou sous un autre format, veuillez nous le demander.

French

જો તમને માહિતી બીજા ભાષા અથવા રચનામાં જોઈતી હોય તો, કૃપા કરી અમને વિનંતી કરો.

Gujarati

यदि आपको सूचना किसी अन्य भाषा या अन्य रूप में चाहिये तो कृपया हमसे कहे

Hindi

ئەگەر زانیاریت بە زمانیکی کە یا بە فۆرمیکی کە دەوی تکایە داوامان لی بکە

Kurdish

Jeżeli chcieliby Państwo uzyskać informacje w innym języku lub w innym formacie, prosimy dać nam znać.

Polish

ਜੇ ਇਹ ਜਾਣਕਾਰੀ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਜਾਂ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ ਚਾਹੀਦੀ, ਤਾਂ ਇਹ ਸਾਥੋਂ ਮੰਗ ਲਵੋ।

Punjabi

Dacă doriți informații în altă limbă sau alt format, vă rugăm să ne întrebați.

Romanian

Молимо вас да нам се обратите ако желите да добијете овај документ на неком другом језику.

Serbian

Haddii aad rabtid in warar lagugu siyo hab luuqadeed o kale, fadlan na soo waydiiso.

Somali

Kama utahitaji taarifa katika lugha nyingine au mtindo mwingine, tafadhali tuambie.

Swahili

தகவலை வேறொரு மொழி அல்லது வேறு வடிவத்தில் பெற விரும்பினால் தயவுசெய்து எம்மைக் கேட்கவும்.

Tamil

Türkçe bilgi almak istiyorsanız, bize başvurabilirsiniz.

Turkish

اگر آپ کو معلومات کسی دیگر زبان یا دیگر شکل میں درکار ہوں تو براۓ مہربانی ہم سے پوچھئے۔

Urdu

Contact Nicola Moran (nem501@york.ac.uk) or Linda Cusworth

(lsc501@york.ac.uk) or telephone 01904 321289.

F5 Summary reply slip



Transition Services for Young People and their Families

Would you like to receive a summary of the research findings?

Yes

No

If **YES**, please fill in your contact details on this sheet and return with your questionnaire in the freepost envelope provided.

Name: _____

Address: _____

THANK YOU

Please return with your questionnaire in the freepost envelope provided.

Appendix G
Family Survey: Reminder Letters

G1 Exemplar 1st reminder letter for parents

[On Letterheaded Paper]

Dear Parent

Re: Transition Services for Young People and their Families – Research Project

We wrote to you recently asking for your help with a research project by filling in a questionnaire about your son/daughter's transition from child to adult services.

This letter is to remind you about the questionnaire and encourage you to complete it. One of the main purposes of this project is to gather information that can help to improve transition services for young people and their families.

If you do not want to fill in the questionnaire and do not want any further contact about the research, please fill in the reply slip below and return it to us in the freepost envelope provided. We will then know not to write to you again.

If you have returned the questionnaire in the past few days, thank you very much for doing so and please ignore this letter.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper



Site code _____

Transition Services for Young People and their Families: Research Project (Parent Post)

I do not want to fill in the questionnaire and do not want any further contact about the research

Your name:

Please return this slip using the freepost envelope enclosed.

G2 1st reminder letter for young people post-transition

[On Letterhead Paper]

Dear Young Person

Re: Transition Services for Young People and their Families – Research Project

We wrote to you recently asking for your help with a research project by filling in a questionnaire about your experience of transition from child to adult services.

This letter is to remind you about the questionnaire and encourage you to complete it. One of the main purposes of this project is to gather information that can help to improve services for young people and their families.

If you do not want to fill in the questionnaire and do not want any further contact about the research, please fill in the reply slip below and return it to us in the freepost envelope provided. We will then know not to write to you again.

If you have returned the questionnaire in the past few days, thank you very much for doing so and please ignore this letter.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

✂-----

Site code _____

Re: Transition Services for Young People and their Families: Research Project (YP)

I do not want to fill in the questionnaire and do not want any further contact about the research

Your name:

Please return this slip using the freepost envelope enclosed.

G3 Exemplar 2nd reminder letter for parents

[On Letterheaded Paper]

Dear Parent

Re: Transition Services for Young People and their Families (Post) – Research Project

We wrote to you some time ago asking for your help with a research project by filling in a questionnaire about your son/daughter's transition from child to adult services.

This letter is a final reminder about the questionnaire. We would still be very pleased to receive a completed questionnaire from you. If you have lost, damaged or misplaced the original questionnaire please ring or email us and we will be happy to send you a further questionnaire.

If you have any questions or need help completing the questionnaire, please call us on 01904 321289. If you would prefer to complete the questionnaire online, please email Linda Cusworth on lsc501@york.ac.uk

If you do not wish to take part in the study we apologise for any inconvenience caused and we will not be writing to you again.

If you have returned the questionnaire in the past few days, thank you very much for doing so and please ignore this letter.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

G4 2nd reminder letter for young people post-transition

[On Letterheaded Paper]

Dear Young Person

Re: Transition Services for Young People and their Families – Research Project

We wrote to you some time ago asking for your help with a research project by filling in a questionnaire about your experience of transition from child to adult services.

This letter is a final reminder about the questionnaire. We would still be very pleased to receive a completed questionnaire from you. If you have lost, damaged or misplaced the original questionnaire please ring or email us and we will be happy to send you a further set of questionnaires.

If you have any questions or need help completing the questionnaire, please call us on 01904 321289. If you would prefer to complete the questionnaire online, please email Linda Cusworth on lsc501@york.ac.uk

If you do not wish to take part in the study we apologise for any inconvenience caused and we will not be writing to you again.

If you have returned the questionnaire in the past few days, thank you very much for doing so and please ignore this letter.

Yours sincerely

Nicola Moran
Research Fellow

Linda Cusworth
Research Fellow

Professor Patricia Sloper

Appendix H

Family Survey: Demographic and Diagnostic Characteristics of Survey Respondents

This appendix provides details on the demographic characteristics of the parents and young people/young adults took part in Stage 3 (surveys of parents and young people/young adults). Data from these surveys are reported in Chapters 5, 6 and 9. This appendix provides information on the samples used in the data analyses for these chapters.

H.1 Sample characteristics for data presented in Chapter 5

Chapter 5 reports young people’s accounts of planning to leave school and, for some, the transfer from school to college. Qualitative and quantitative evidence is presented. The quantitative data comes from the questionnaire completed by young people aged 13–18 years. The characteristics of this survey are reported here. Fifty-six young people returned a ‘pre-transition’ questionnaire. However, data on their demographic and diagnostic characteristics was only collected in the parents’ questionnaire. Fifty (90%) of these young people’s parents also completed a questionnaire. Our analysis was restricted to this group in order that we had a knowledge of respondents’ demographic and diagnostic characteristics.

The majority of respondents were male (82%). Parent-reported ASC diagnosis¹ were as follows: high functioning autism (HFA)=12%; Asperger’s syndrome=52%; autism=30%; ASC=16%. The mean age of respondents was 15.6 years and all respondents were White. A third of respondents had been diagnosed with ASC during their pre-school years, and six out of ten had been diagnosed as a primary-school aged child. Three-quarters of respondents were living in families where paid employment was the main family income.

The young people’s questionnaires were provided to each potential respondent in three versions: full version; short version (fewer questions included); and a symbols-based version which replicated the short version. Forty-six per cent of respondents completed the full version (n=23) with the remainder completing either the short versions, of whom a quarter used the symbols-based version.

Young person’s gender (n=50)

	N	%
Male	41	82%
Female	9	18%

¹ Parent-reported diagnosis of ASC is difficult to interpret. In this instance, we made the assumption that if a diagnosis of HFA or Asperger’s syndrome had been given parents would prefer to state this than simply to report ‘autism’ or ‘ASC’. Based on this assumption, we would argue that just under half the sample (46%) young people with ASC and some degree of learning disability.

Parent-reported diagnosis (open-response question) (n=50)

	N	%
High Functioning Autism	6	12%
Asperger's syndrome	21	52%
Autism	15	30%
ASC	8	16%

Young person's age (n=50)

	N	%
13	3	6%
14	10	20%
15	14	28%
16	8	16%
17	8	16%
18	7	14%
<i>Mean age=15.6 yrs</i>		

Young person's ethnicity (n=50)

	n	%
White	50	100%

Parent-reported age at diagnosis (n=49)

	N	%
4 years or under	16	33%
5 – 11 years	29	59%
12 years or older	4	8%

Parent who completed paired questionnaire: relationship to young person (n=50)

	N	%
Mother	42	84%
Father	7	14%
Other	1	2%

Parent who completed paired questionnaire: marital status (n=50)

	N	%
Married or long-term relationship	36	72%
Single	7	14%
Separated/divorced	7	14%

Main source of family income (n=48)

	N	%
Paid employment	36	75%
Social security benefits	12	25%

Questionnaire completed by young person (n=50)

	N	%
Full version	23	46%
Short version	21	42%
Symbol version	6	12%

H.2 Sample characteristics for data presented in Chapter 6

Chapter 6 is concerned with parents' reports of the experiences of planning for leaving school. In presenting evidence from the parents' survey we selected two sets of parent respondents:

- i) Those whose child was still in school, that is had not transferred to college or any other setting at 16 years. These respondents were, therefore, currently planning for leaving school. Of the 105 parents who completed the 'pre-transition' survey, 70 (66%) fulfilled this inclusion criteria. We refer to this as the 'in-school' sample.
- ii) Those whose child was no longer in school or further education, or the 'post-18 sample'.

The characteristics of these two groups of parents are described below.

The 'in-school' sample

The great majority of respondents comprising the 'in-school sample' were mothers (83%). Three quarters were living in families where the main source of income was paid employment.

As expected, the sample represented mainly boys (86%). An open-response question regarding the child's diagnosis generated the following responses: High Functioning Autism

(HFA)=13%; Asperger’s syndrome=29%; Autism=43.5% and ASC=14.5%². Most (93%) had been diagnosed with ASC as pre-schoolers or primary-school aged children. The ages of young people ranged from 13 to 18 years, with a mean age of just over 15 years and the majority were White.

The following tables provide this information about the ‘in-school’ parent sample in more detail.

Parent’s relationship to child (n=70)

	N	%
Mother	58	83%
Father	12	17%

Child’s gender (n=70)

	N	%
Male	60	86%
Female	10	14%

Parent-reported diagnosis (open-response question) (n=69)

	N	%
High Functioning Autism	9	13%
Asperger’s syndrome	20	29%
Autism	30	43.5%
ASC	10	14.5%

Child’s age (n=70)

	N	%
13	6	9%
14	17	24%
15	25	36%
16	9	13%
17	8	11%
18	5	7%
<i>Mean age=15.1 yrs</i>		

² Parent-reported diagnosis of ASC is difficult to interpret. In this instance, we made the assumption that if a diagnosis of HFA or Asperger’s syndrome had been given parents would prefer to state this than simply to report ‘autism’ or ‘ASC’. Based on this assumption, we would argue that over half the sample (58%) were parents of young people with ASC and some degree of learning disability. This is substantially different to the ‘post 18’ sample of parents.

Child's ethnicity (n=70)

	N	%
White	66	94%
Black African	2	3%
Indian	1	1.5%
Other	1	1.5%

Parent-reported age at diagnosis (n=69)

	N	%
4 years or under	30	44%
5 – 11 years	34	49%
12 years or older	5	7%

Parents' marital status (n=69)

	N	%
Married or long-term relationship	49	71%
Single	8	12%
Separated/divorced	12	17%

Main source of family income (n=65)

	N	%
Paid employment	49	75%
Social security benefits	16	25%

The 'post-18 sample'

Just 29 parents (response rate=26%) completed the 'post-transition' survey questionnaire. The great majority of respondents mothers (90%). Three-quarters were living in families where the main source of income was paid employment.

As expected, the sample represented mainly boys (82%). An open-response question regarding the child's diagnosis generated the following responses: High Functioning Autism (HFA)=7%; Asperger's syndrome=68%; Autism=14% and ASC=11%³. Most (71%) had been

³ Parent-reported diagnosis of ASC is difficult to interpret. In this instance, we made the assumption that if a diagnosis of HFA or Asperger's syndrome had been given parents would prefer to state this than simply to report 'autism' or 'ASC'. Based on this assumption, we would argue that around a quarter of the sample (25%) were parents of young people with ASC and some degree of learning disability. This is substantially different to the 'in-school' sample of parents.

diagnosed with ASC as pre-schoolers or primary-school aged children. The ages of young people ranged from 18 to 24 years, with a mean age of just over 20 years and the majority were White.

The following tables provide this information about the 'post-18' parent sample in more detail.

Parent's relationship to child (n=28)

	N	%
Mother	26	90%
Father	3	10%

Child's gender (n=28)

	N	%
Male	23	82%
Female	5	18%

Parent-reported diagnosis (open-response question) (n=28)

	N	%
High Functioning Autism	2	7%
Asperger's syndrome	19	68%
Autism	4	14%
ASC	3	11%

Child's age (n=28)

yrs	N	%
18	1	4%
19	12	43%
20	7	25%
21	3	7%
22	3	10.5%
24	3	10.5%
<i>Mean age=20.2 yrs</i>		

Child's ethnicity (n=27)

	N	%
White	24	89%
Indian	1	4%
Other	1	7%

Parent-reported age at diagnosis (n=28)

	N	%
4 years or under	2	7%
5 – 11 years	18	64%
12 years or older	8	29%

Parents' marital status (n=28)

	N	%
Married or long-term relationship	25	86%
Single	1	4%
Separated/divorced	3	10%

Main source of family income (n=28)

	N	%
Paid employment	22	76%
Social security benefits	6	24%

H.3 Chapter 9

Chapter 9 draws on data from the post-18 parents sample (see previous section) and data collected from post-18 young people.

Twenty young people over 18 years returned a questionnaire. However, data on their demographic and diagnostic characteristics was only collected in the parents' questionnaire. Thirteen of these young people's parents also completed a questionnaire. Our analysis was restricted to this group in order that we had a knowledge of respondents' demographic and diagnostic characteristics.

The majority of respondents were male (n=10/13). Parent-reported ASC diagnosis⁴ were as follows: high functioning autism (HFA)=2; Asperger's syndrome=10; autism=1. The mean age of respondents was 20.2 years and all but one of the respondents were White. Most (10/12; missing data=1) had been diagnosed with ASC during their primary-school years. Eight were living in families where paid employment was the main family income, and five where the main family income was social security benefits.

The young people's questionnaires were provided to each potential respondent in three versions: full version; short version (fewer questions included); and a symbols-based version which replicated the short version. The great majority completed the full version (10/13) with the remaining three completing either the short versions, of whom a two used the symbols-based version.

Young person's gender (n=13)

	N ⁵
Male	10
Female	3

Parent-reported diagnosis (open-response question) (n=13)

	N
High Functioning Autism	2
Asperger's syndrome	10
Autism	1

Young person's age (n=13)

Yrs.	N
19	6
20	3
21	1
22	2
23	0
24	1
Mean age=20.2 yrs	

⁴ Parent-reported diagnosis of ASC is difficult to interpret. In this instance, we made the assumption that if a diagnosis of HFA or Asperger's syndrome had been given parents would prefer to state this than simply to report 'autism' or 'ASC'. Based on this assumption, we would argue that just under half the sample (46%) young people with ASC and some degree of learning disability

⁵ Frequency counts only reported due to small sample size.

Young person's ethnicity (n=13)

	N
White	12
Other	1

Parent-reported age at diagnosis (n=12)

	N
4 years or under	0
5 –11 years	10
12 years or older	2

Parent who completed paired questionnaire: relationship to young person (n=13)

	N
Mother	12
Father	1

Parent who completed paired questionnaire: marital status (n=13)

	N
Married or long-term relationship	10
Single	1
Separated/divorced	2

Main source of family income (n=13)

	N
Paid employment	8
Social security benefits	5

Questionnaire completed by young person (n=13)

	N
Full version	10
Short version	1
Symbol version	2

Appendix I
Parent Recruitment Materials

I1 Parent covering letter for interview

[On Letterhead Paper]

KW/

Name and address

Heslington, York, YO10 5DD

Telephone: (01904) 321950

Fax: (01904) 321953

Website: www.york.ac.uk/inst/spru

E-mail: katharine.weston@york.ac.uk

Date

Dear [*Parent name*]

Research study: Transition to adult services and adulthood for young people with autistic spectrum conditions

We are researchers at the Social Policy Research Unit at the University of York. You may remember completing a questionnaire at the end of last year about your child's transition to adult services and adulthood. We are writing to you because you indicated an interest in being interviewed about your family's experiences by supplying us with your contact details.

We have now reached the next stage of our research study, which involves interviews with parents/carers and young people with autistic spectrum conditions (ASC). The research is funded by the Department of Health and is being carried out in five areas in England. The purpose of the research is to provide information that can help to improve services for young people with ASC and their families during transition from children's to adult services. We are carrying out interviews with parents and young people because we want to understand their experiences of transition and to find out what aspects of service provision work for them and those that do not work. An information leaflet about the study is enclosed and we hope that you find it useful.

In a week or so, either Katharine or Gemma will get in touch with you by telephone to tell you more about the research, answer any questions that you have and ask if you would be willing to take part in an interview. Please be assured that taking part is voluntary and will not affect any dealings you have with any government department or agency. If you agree to take part, the researcher will ask whether you prefer to be interviewed in person or over the phone and make arrangements accordingly. They will also discuss any requirements you may have which will make it easier for you to take part. The interview is expected to last around 60-90 minutes. Anything you discuss with the researchers will be kept confidential in accordance with the Data Protection Act.

Continued/...

.../2

If your son/daughter completed our questionnaire and indicated that they would like to be contacted about taking part in an interview, we can also discuss this with you. The interviews with young people will be conducted by our colleague, Wendy Mitchell, and she will write to them separately. If you feel it would be most convenient for the parent and young person interviews to take place during the same visit, we can make arrangements to do so.

If you and/or your child decide that you do not want to be interviewed, this is not a problem and you do not need to give a reason. You can let us know by telephone (01904 321950), by email (katharine.weston@york.ac.uk), or by post using the Unit address on the letter heading.

Finally, if you have any questions about this research, please do not hesitate to get in touch with us.

Yours sincerely

Katharine Weston and Gemma Spiers
Researchers

Enc.

12 Parent information sheet for interview

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions - Research Project

Information Leaflet for Parents/Carers

Thank you for completing the questionnaire. This leaflet provides information about the final stage of our research, which involves interviews with parents/carers and with young people with autistic spectrum conditions (ASC).

What is the aim of the research?

The aim of the research is to provide information that can help to improve services for young people with ASC and their families during transition from children's to adult services. The research is being carried out in five areas in England.

Who is undertaking the study and how is it funded?

The study is based at the Social Policy Research Unit (SPRU) at the University of York and is funded by the Department of Health. The research team members are Bryony Beresford, Nicola Moran, Linda Cusworth, Katharine Weston, Gemma Spiers and Wendy Mitchell.

What am I being asked to do?

By supplying your contact details on the questionnaire you indicated that you would be willing for us to contact you about being interviewed in the final stage of the research. The interview would involve a researcher coming to visit you at your home, or any other convenient place, at a date and time to suit you. Alternatively, we could interview you over the telephone. We expect the interview to last between 60 and 90 minutes and we would like to record the interview, but we will ask your permission before we start. If you prefer not to be recorded, we will take notes.

If your son/daughter is interested in taking part, we would also like to interview him/her. We can discuss the best way of doing this if your son's/daughter's preferred method of communication is not speech. We do everything we can to make our interviews accessible. We could see your son/daughter when we visit to interview you, or at another time. **If you would like to take part but your child does not wish to, or vice versa, that is ok.** We are interested in everyone's views.

What questions will you ask me?

Topics will include:

- planning for your son/daughter leaving school and experiences of doing so
- planning for your son/daughter moving on from children's to adult services and experiences of doing so
- the extent to which your son's/daughter's needs have been met

- your views on what could be done to improve transition services.

Why should I take part?

By involving parents/carers and young people in our research we hope to inform service providers about people's experiences of transition. By doing this, we hope that in the future, transition services for young people with ASC and their families will get better.

Do I have to take part?

No, you do not have to take part. If you decide not to take part that is OK, you do not have to give a reason. Whether or not you decide to take part will not affect any services that your family receive.

What will happen to the information?

All information collected during the course of the research will be kept strictly confidential in line with the Data Protection Act. Data will be kept in locked storage for five years from the end of the study and then destroyed. We will not discuss what you have told us with anyone and we will not tell anyone that you have taken part. However, if you or your son/daughter says anything that makes the researcher think that they are at risk of harm, the researcher will have to tell the appropriate authorities. The researcher will speak to you about this before they speak to somebody else.

When we have completed the research we will produce a report which will include the views of everyone who has taken part but will not identify anyone. The report will include recommendations about the best ways to meet the needs of young people with ASC and their families at the time of transition. We will send you a summary of the report if you would like one. The report will also be sent to the government who are funding the research.

What happens next?

We will contact you in the next few weeks to find out if you would like to take part in an interview. If you are happy to be interviewed we can arrange when and where to meet. In the meantime, if you have any questions about the interview, please contact the research team using the contact details below.

Katharine Weston

katharine.weston@york.ac.uk

Gemma Spiers

gemma.spiers@york.ac.uk



01904 321950

Fax: 01904 321953



Social Policy Research Unit
University of York
Heslington
York
YO10 5DD

For more information on SPRU visit: www.york.ac.uk/inst/spru/

Thank you for your time.

Appendix J
Parent Fieldwork Instruments

J1 Parent consent form

**Transition Services for Young People with Autistic Spectrum
Conditions Research Project**

Consent Form for Parents/Carers

Please tick:

I have read the project information leaflet and understand the purpose of the project and what is involved Yes No

I understand that the information I provide is strictly confidential and I will not be named in any project reports. Yes No

I understand that participation is voluntary and that I can withdraw from the project at any time without giving a reason. Yes No

I understand that if I say anything that makes the researchers think that my son/daughter is at risk of harm, they will have to tell the appropriate authorities but they will tell me before they do this. Yes No

I am willing to be interviewed as part of this research. Yes No

I agree for my interview to be digitally recorded. Yes No

Name of participant: **Signature:**

Name of researcher:

Signature of researcher:

Date:

Transition to adult services and adulthood for young people with autistic spectrum conditions:

Parent interviews topic guide

Introduction

- Introduce self and study.
- Interview expected to last 1 – 1 ½ hours.
- Explain confidentiality (including its limits in event of disclosure) and anonymity, how data and quotes will be used.
- Explain their right to withdraw at any time and that they do not have to answer any questions they don't want to.
- Check it is okay to record interview; explain that only the research team will have access to the recordings and transcripts.
- Ensure consent form signed.

A. Background to young person's condition and associated needs

Q1. What words do you use to describe your son's/daughter's condition, and would like me to use throughout our discussion?

- Examples of areas where son/daughter has particular difficulties (*refer to throughout subsequent discussion*)
 - difficulties regarding moves towards independence/doing things for the first time (e.g. money, transport, personal safety) or leaving school
- Confirm type of school attended and whether he/she had a SEN

B. Experiences of planning ahead for transfers and changes

Q2. We're interested in hearing about your experiences of planning for changes in your son's/daughter's life as they move towards adulthood, particularly leaving school and transfers from children's services to adult services in social care and health.

Have any changes taken place yet, or have you started planning for changes? [*Use timeline to show when changes took place*].

- Probe for leaving school and what son/daughter has done since (e.g. further education, higher education, paid work, voluntary work, other daytime activities).
- Probe for transfer/changes in social care services (e.g. short breaks and family support).
- Probe for transfer/changes in health care services (inc. CAMHS to AMHS).
- Probe for changes to other services/support/clubs (inc. whether they stop at a certain age).
- Check for contact with multi-agency transition service (*refer to list of services known to be in area*).
- Do/did you have one named person for transition support? *If yes:*
 - Has/did this person remain(ed) your named contact throughout the process (so far)?

Q3a. We want to understand whether and how changes/transfers are planned for. Starting with plans for leaving school, can you talk me through the planning processes so far?

- How was the planning process instigated? Did you instigate it or did statutory services?
- Do/did you or your son/daughter have any ideas about what they would do when they left school? (e.g. residential setting, further/higher education, employment, voluntary work)
 - What work is being done/was done (e.g. by school/other) to prepare them for this?
- What is/was involved in planning for and making the transfer from school?
 - When did this happen? [*use timeline*]
 - Who is/was involved?

Q3b. Now I'd like to ask about the transfer from children's services to adult services/no services (health and/or social care). Can you talk me through the planning processes so far?

- Probe for transfer in social services.
- Probe for transfer in health services; CAMHS to AMHS.
- Probe for transfer from other services/support/clubs to no support.

For each type of transfer/change:

- How was the planning process instigated? Did you instigate it or did statutory services?
- What happened/is happening and when? [*use timeline*]
- Who is/was involved?
- Has your son/daughter been provided with an Individual Budget (in past or now)?
 - How was/is this managed? In whose name was/is it held?
 - Experiences of handing over responsibility for budget to son/daughter.
- Check for any major changes in circumstances during planning process – inc. changes in schools and moves between Local Authorities

Q4. Other than the Local Authority (including social services, education and Connexions) and health services, have you received any help or advice from anyone else (e.g. voluntary organisations, local support groups)?

- Check for Parent Partnership Service involvement.
- When and how did you come to receive help from this source?
- What help do/did they provide?

C. Views about the process of planning ahead for transfers and changes

Q5. What did you think about the support received to make these transfers/changes?

➤ *Prompt for all transfers (school, health, social care).*

- Views about timing of support (e.g. too early, too late) and regularity/frequency of contact.
- Views about the people involved: skills, knowledge, attitudes, continuity, time available.
- Was the support from these people/services 'joined up'? Implications for transition planning.
- To what extent did you feel actively involved in transition planning? Extent son/daughter involved?
 - Probe for facilitators and barriers to parent/young person involvement.
 - Extent to which young person's particular difficulties/needs were taken into account.
- To what extent did you feel supported by transition worker/team/services to make decisions, or to help your son/daughter make decisions about the future?
- Views about support received from other/non-statutory services.
 - How this support compared with statutory support.
 - Parent Partnership Services.
- What has worked well in the transition planning process?
- What has not worked so well?
- Have you had opportunities to give feedback to services about your experiences?

D. Impact of transfers and changes so far

Q6. Thinking about impending changes:

- How are impending changes impacting on your son/daughter?
- How is the planning for transition impacting on you?
 - What has been most difficult in the planning process
- What are your concerns about impending changes/future?
 - What would help to alleviate these concerns?

Q7. *(If appropriate)* Thinking about the transfers and changes your son/daughter has experienced already:

- How have these changes affected your son/daughter? E.g. health (esp. stress), socially.
 - *If appropriate*: probe for impact of transfer from support to no support.
- How have these changes affected you? E.g. health (esp. stress), employment situation, caring responsibilities, housing situation.
 - *If appropriate*: probe for impact of transfer from support to no support.

E. Transition outcomes so far and future needs and concerns

If young person has left school:

Q8. Was your son/daughter looking forward to anything in particular about leaving school? What were their hopes?

(N.B. If the answer to this question is 'no' or it does not fit their circumstances, ask for parents' aspirations for their son/daughter.)

- Probe for the following:
 - Education, employment, meaningful daytime activities – and whether mainstream provision or specialist autistic provision or provision for disabled people.
 - Independent living.
 - Social life (e.g. leisure, friendships).
- Have these hopes and aspirations been achieved?
 - Why/why not?

Q9. What's happening now for your son/daughter?

- What services are being used by your son/daughter? Who is involved (e.g. PA, transition worker)?
- Where are you at now in the planning process?
 - Probe for whether further contact is planned/needed with services to complete the transfer:
 - from school to adult occupation?
 - from children's services to adult services/no services.
- What needs are outstanding?
 - Probe for any needs for social care support or health care support.
 - Probe for ongoing social skills/communication needs; independent living needs.
 - What would help to meet these needs?
- How well do you feel your son/daughter is supported at the moment?
 - *If appropriate:* How does the support from adults' services compare with children's services?
 - What are your hopes/expectations regarding continued/future support?
- What concerns do you have now about:
 - Impending changes?
 - Your son's/daughter's future?
 - what would help to alleviate these concerns?

F. Overall views and suggested improvements

Q10. Finally, can you sum up the main messages you would like to give to service managers or to government about needs and support during transition?

- What works well; any positive experiences?
- What does not work so well; any negative experiences?
- To what extent does/did transition planning make a difference? What would be happening/have happened without it?
- What changes should be made to improve the support for transition?
- What advice would you give to parents of young people who are about to start the transition process?

[End of interview]

- Thank parent for participation.
- Use 'Household composition form' to ask for additional details about the family.
- Check that they are happy for us to use all the information they have given and remind about confidentiality.
- Feedback details.
- Give parent support leaflet.

J3 Household composition form

Participant code: _____

HOUSEHOLD COMPOSITION FORM

Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Disorders

Refer to details recorded in survey response, and double check at interview if these are still correct.

Parent's age: _____

Employment status

Mother: Employed/Self-employed/not in employment/retired
If working: Part-time/full-time

Father: Employed/Self-employed/not in employment/retired
If working: Part-time/full-time

Child's age: _____

Child's Diagnosis: _____

In receipt of DLA? Yes/No

Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions

Support Leaflet for Parents Taking Part in this Research

Thank you very much for taking part in this research.

It is possible that taking time to reflect on the support and services your son/daughter receives during their transition to adulthood may lead you to feel that you would like more information or advice, or to become concerned about your own or your child's wellbeing. If you have concerns, the best people to contact may be your local team or GP.

This leaflet describes some additional sources of advice and support which you may find useful.

Parent Partnership Services

Parent Partnership Services is a statutory service offering support to parents of young people with a special educational need. Their website offers a range of information and support, and the contact details of your local PPS are below:

[Local contact details]

<http://www.parentpartnership.org.uk/>

National Charities/Organisations

National Autistic Society

The National Autistic Society (NAS) is a UK-wide organisation and has over 100 local branches. It provides a range of information and support for individuals with autism, and their families. This support includes an Autism Helpline, online forums, a signposting facility to find local services, and a telephone support service specifically for parents (*Parent to Parent*).

Further information about these support services are listed below.

Autism Helpline:

Telephone: 0845 070 4004 (10am-4pm, Monday-Friday)

Text: 07903 200 200

By post: Autism Helpline
The National Autistic Society
393 City Road
London, EC1V 1NG

Website: <http://www.autism.org.uk/Our-services/Advice-and-information-services/Autism-Helpline.aspx>

Online forums

The link below takes you to the online discussion forums:

<http://community.autism.org.uk/>

Signposting facility

This is an online search facility where you can search for services specific to your needs. The link below takes you to the signposting service:

<http://www.autism.org.uk/signpost>

Parent to Parent

This is a confidential telephone support service for parents or carers of an adult or child with autism. You can contact this service either telephone or through an online enquiry form.

Telephone: 0800 9 520 520

Further information about the Parent to Parent service is available online at:
<http://www.autism.org.uk/Our-services/Advice-and-information-services/Parent-to-Parent-Service.aspx>

Contact details for NAS

393 City Road
London
EC1V 1NG

Website: www.autism.org.uk
Telephone: 020 7833 2299
Email: nas@nas.org.uk

Mencap

Mencap is a national organisation providing information and support to individuals with learning disabilities (including autism) and their families. The mencap website also has an online forum for families.

Contact details for Mencap

123 Golden Lane
London
EC1Y 0RT

Website: www.mencap.org.uk
Telephone: 020 7454 0454
Email: Information@mencap.org.uk

Family Lives

Family Lives is a national charity providing support in all aspects of family life. They offer a telephone helpline (*Parentline*), email support, online chat forums and a range of information and free resources.

Contact details for Family Lives

General enquiries:	Website:	parentsupport@familylives.org.uk
CAN Mezzanine	Telephone:	020 7553 3080
49-51 East Road	Parentline:	0808 800 2222
London N1 6AH		

Email support and online chat forum: <http://familylives.org.uk/how-we-can-help>

The Princess Royal Trust for Carers

The Princess Royal Trust for Carers is a national charity that campaigns on behalf of carers. It offers support and advice, including an online discussion forum and chat room (see link below)

Website: <http://www.carers.org/carers-chat>

Transition Information Network

The Transition Information Network (TIK) website provides information for those who are supporting young people with a disability through the transition process.

Website: <http://www.transitioninfonetwork.org.uk/home1.aspx>

The TIK website also has a section for young people:

Website: http://www.transitioninfonetwork.org.uk/young_people.aspx

Appendix K
Young Person Recruitment Materials

K1 Young person covering letter for interview

[On Letterheaded Paper]



Dear

Re: In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

My name is Wendy and I work at the Social Policy Research Unit at the University of York on the 'In Transition: Young people with autistic spectrum conditions (ASC) growing up and planning for the future' study.

Last year you filled in a questionnaire about transition help and support. I've photocopied the front page of the questionnaire in case you've forgotten what it looked like. It's attached to the back of this letter. The aim of the research is to help improve services and support for young people with ASC and their families as they leave school or college, move to adult services and plan for the future.

I'm writing to you because you said you might like to help with the final part of the study. The final part involves interviewing young people and some of their parents. Interviews will ask young people about their ideas and experiences of transition. The interview will take about 60 minutes. You can tell me about your ideas by talking to me, writing things down or using pictures. You can choose. The (green) information sheet tells you more about the study.

In the next two or three weeks, I will ring you (or your parents) to tell you more about being interviewed. If you have any questions, you can ask me when I ring. If you say 'yes', I will arrange a day and time to come and talk to you.

Continued/...

.../2

You don't have to take part in the study, you can say 'no'. You don't have to give a reason but if you don't want to be interviewed, please can you let me know by ringing (01904 321950), emailing (wendy.mitchell@york.ac.uk) or writing to me (SPRU's address at the top of this letter).

Thanks for your help.

Best wishes



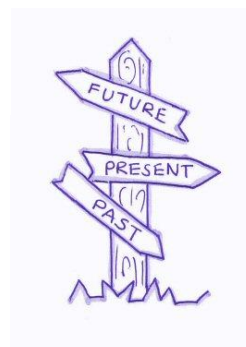
Wendy Mitchell

Enc

K2 Young person information sheet for interview

THE UNIVERSITY *of York*

spru | Social Policy
Research Unit



In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Information Leaflet for Young People

Thank you for filling in the University of York transition and moving on study questionnaire. This leaflet tells you about the last part of the research, interviewing young people with autistic spectrum conditions (ASC).

What is the aim of the research?

The aim of the research is to help improve services and support for young people with ASC and their families, as they leave school or college, move to adult services and plan for the future. The research is taking place in five areas in England.




Who is doing the study and how is it funded?

Most of the researchers work at the Social Policy Research Unit (SPRU) at the University of York. It is funded by the Department of Health. Wendy Mitchell is the researcher interviewing young people.

What am I being asked to do?

When you filled in the questionnaire last year, you gave us your address and said it would be OK to contact you about being interviewed.

If you decide to be interviewed, Wendy will come to your house to talk to you or you can choose to meet her somewhere else. Wendy wants to hear your ideas and experiences of:

-  Preparing to leave school or college.
-  Moving from children's to adult services.
-  Growing up and becoming an adult.

When you meet Wendy you can tell her what you think by talking, writing things down or using pictures. You can choose.

Why should I take part?

Telling Wendy about your ideas and experiences is important. It will help us tell professionals what young

people with ASC think about the support they get at transition when they leave school and plan for the future. We hope it will help make services better in the future.

Do I have to take part?

No, you don't have to take part; saying 'no' is OK. It won't affect any services or help you get. You can also stop taking part before or during your interview. You don't have to give a reason.

What will happen to the information I give?

The recorded and written information will be kept safe in a locked cupboard and all computers will have a password. Information will only be looked at and listened to by Wendy and the other people who work on the study.

Wendy will not tell anyone what you say in the interview. But, if you tell Wendy that you or someone else is being hurt, she might have to tell someone else. Before Wendy does this, she will talk to you about it.

At the end of the project, Wendy and the other people working on the study will write a report. We may use things you've said but we won't use your name. Wendy will send

you a summary of the report if you want one. The report will also be sent to the Department of Health.

What happens next?

Wendy will contact you in the next few weeks to tell you more about being interviewed. If you say 'yes' and want to be interviewed, Wendy will arrange a day and time to visit you.

If you have any questions, contact Wendy by:



01904 321950



wendy.mitchell@york.ac.uk

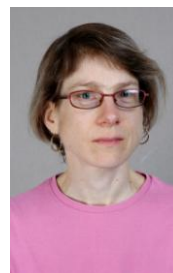


Social Policy Research Unit
University of York
Heslington
York YO10 5DD

More information about SPRU: www.york.ac.uk/inst/spru/

Thank you for your help.

Wendy Mitchell



Appendix L
Young Person Fieldwork Instruments

L1 Young person consent form

In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Young People's Consent Form

If you have any questions talk to Wendy before you fill in this form. Wendy will keep a copy of this form and give you a copy to keep.

Please tick the boxes



Yes



No

- | | | |
|--|--------------------------|--------------------------|
| I have read the information sheet | <input type="checkbox"/> | <input type="checkbox"/> |
| I have had time to think about taking part | <input type="checkbox"/> | <input type="checkbox"/> |
| I have asked questions if I wanted to | <input type="checkbox"/> | <input type="checkbox"/> |
| I know I do not have to take part | <input type="checkbox"/> | <input type="checkbox"/> |
| I know I can stop taking part if I want to | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree that you can record our conversation | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to take part in the research | <input type="checkbox"/> | <input type="checkbox"/> |

Participant's name

Signature

Date

Parent's name*

Signature

Date

Researcher's name

Signature

Date

* Written parental consent will be requested for young people under 18 years old.

In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Pre-school Leaving YP Topic Guide

A. Introduction

NB: Complete the 'My Life' chart if appropriate with YP, when asking:

What things do you think will be different in your life when you leave school?

Show List:

- College/employment
- Friends
- Things I do in my free/spare time
- Doing more 'grown up things', doing things independently
- People who help me, professionals I see

B. Moving On From School

NB: Complete the 'Moving on from school – leaving X' chart if appropriate with YP, when asking:

What Next?

1. What will you do/are you planning to do when you leave school?
2. Is this what you want to do?
If wanted, probe The place they want to go to, the course/thing they want

If not wanted, probe What wants to do, what's stopping them
3. Was anything else suggested that you could do?
Probe What

Planning, Support and Feelings

- 1. Who's been helping you plan leaving X (school) and going to Y (college/work)?**
[Help from professionals, family, friends, such as giving you information, organising visits to/spending time at college/work, helping you talk to people at college/work]

Probe Who, level and type of support
What they've been doing/helping with
If helpful and what's been most helpful
If would like more help (what)
- 2. It seems as if lots of things have been talked about or are happening, are you enjoying making plans to leave X (school) and go to Y (school/college)?**

Probe What/what not enjoying (why)
- 3. Is there anything you'll miss about X (school)?**

Probe What and why
- 4. Is there anything you won't miss?**

Probe What and why
- 5. Do you have any worries/concerns about leaving X (school)?**

Probe What and why
- 6. Have you talked to anyone about this? [Such as school staff, family, friends, professionals]**

If has talked, probe Who and what suggested/done/help given
If helpful and what's been most helpful
If wants more help (what)

If hasn't talked, probe Why not
- 7. What sort of things are you looking forward to about going to Y (college/work)?**

Probe What and why
- 8. Is there anything you're not looking forward to/worried about at Y (college/work)?**

Probe What and why
- 9. Have you talked to anyone about this? [Such as school staff, college/work staff, family, friends, professionals]**

If has talked, probe What suggested/done/help given
If helpful and what's been most helpful
If wants more help (what)

If hasn't talked, probe Why not

C. Services That Help Me

NB: Complete the 'Services that help me' chart if appropriate with YP, whilst asking:

Lots of different people help YP; do any of these people help you?

Show List

- Social workers
- Doctors
- Psychologists
- Community nurses
- Counsellors
- Speech and language therapists

Or, do you go to any special clinics or centres to talk about your autism?

Probe Who sees or visits

What Next?

1. Do you think this will change in the next few years?

Probe What will change and when change expected

Planning, Support and Feelings

If change expected ask:

1. Who's been helping you to plan this change?

Probe

- Level and type of support
- What they've been doing/helping with
- If helpful and what's been most helpful
- If would like more help (what sort)

2. Is there anything you'll miss about not seeing (name of professional) or going to (name of clinic/centre)?

Probe What and why

3. Is there anything you won't miss?

Probe What and why

4. Do you have any worries or concerns about leaving (name)?

Probe What and why

5. Have you talked to anyone about this? [Such as family, friends, professionals]

If has talked, probe

- What suggested/done/help given
- If helpful and what's been most helpful
- If wants more help

If hasn't talked, probe Why not

6. **Is there anything you're looking forward to/you think will be better about having a new/different (name of professional) or going to a new/different (name of clinic/service)?**

Probe What and why

D. Growing Up

NB: Complete the 'Growing up' chart if appropriate with YP, when asking:

When people talk about growing up and becoming an adult they often mean things like:

Show List Travelling about by yourself
Doing different things in your spare time
Going out with friends or by yourself
Having a boyfriend or girlfriend
Earning a bit of money
Sorting out your own money (having your own bank account)
Moving away from home or living with new people

What Doing and Feelings

1. **Now you're older, have you started doing any of these things?**

Probe What

2. **Are you enjoying doing (new thing)?**

Probe Why and how much/why not

3. **Was it difficult/hard to start doing (new thing)?**

Probe Why/why not

Planning and Support

1. **Has anyone helped you do (new thing)?** [*Such as family, friends or professionals*]

Probe Who, level and type of support
What they've been doing/helping with
If helpful and what's been most helpful
If would like more help (what)

2. **Are you still getting any help with (new thing)/learning to do (new thing)?**

Probe Level and type of help still getting
If happy with this
If helpful and what's been most helpful
If would like to continue getting help (what)

- 3. Are there any things [show list card] that you're not doing now but you'd like to do now?**

Probe

What and why

What's stopping them

Future Aspirations

- 1. We've talked about new things that you're now doing or want to do now; in the future, what other sorts of things [show list card] would you like to do/do more of?**

Probe

What and why

- 2. In five years time, when you're (insert age), do you think you'll be doing/have (new thing)**

Probe

Why thinks will/will not be doing/have

If thinks will need any help

If help needed, who will help and how

L3 Young person short topic guide pre-transition

In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Pre-school Leaving YP – Simpler Topic Guide

A. Introduction

NB: Complete the 'My Life' chart if appropriate with YP, when asking:

What do you think will change in your life when you leave school?

Show List:

- College/employment
- Friends
- Things I do in my free/spare time
- Doing more 'grown up things', doing things independently
- People who help me, professionals I see

B. Moving On From School

NB: Complete the 'Moving on from school – leaving X' chart if appropriate with YP, when asking:

What Next?

4. What are you going to do when you leave X (school)?

5. Is this what you want to do?

If wanted, probe Place they want to go to, course/thing they want

If not wanted, probe What wants to do, what's stopping them

Planning, Support and Feelings

10. Who's been helping you think about leaving X (school)?

[Help from professionals, family, friends, such as giving information, organising visits to/spending time at college/work, helping YP talk to people at college/work]

Probe Who and what help given
If helpful and what's most helpful
[If wants more help]

11. What things will you miss about X (school)?

Probe What and why

12. What things won't you miss at X (school)?

Probe What and why

13. Have you talked to anyone about this? *[Such as school staff, family, friends, professionals]*

If has talked, probe Who and what suggested/done/help given
If helpful and what's been most helpful
[If wants more help]

If hasn't talked, probe Why not

14. What are you looking forward to at Y (college/work)?

Probe What and why

15. Is there anything you're worried about at Y (college/work)?

Probe What and why

16. Have you talked to anyone about [insert worry]? *[Such as school staff, college/work staff, family, friends, professionals]*

If has talked, probe What suggested/done/help given
If helpful and what's been most helpful
[If wants more help]

If hasn't talked, probe Why not

C. Services That Help Me

NB: Complete the 'Services that help me' chart if appropriate with YP, whilst asking:

Lots of different people help YP; do any of these people help you?

Show List Social workers
 Doctors
 Psychologists or counsellors
 Community nurses
 Speech and language therapists

Or, do you go to any special clinics or centres to talk about autism?

Probe Who sees or visits

What Next?

2. Do you think you'll have a new [name of profession] when you go to Y (college/work)?

Probe [Why/why not]

Planning, Support and Feelings

If change expected ask:

7. Has anyone talked to you about this?

Probe Who and what they've said/been doing
 If helpful and what's been most helpful
 [If would like more help]

8. What will you miss about not seeing (name of old professional)/going to (name of clinic/centre)?

Probe What and why

9. What sorts of things won't you miss?

Probe What and why

10. Have you talked to anyone about [insert]? [Such as family, friends, professionals]

If has talked, probe Who and what suggested/done/help given
 If helpful and what's been most helpful
 [If wants more help]

If hasn't talked, probe Why not

D. Growing Up

NB: Complete the 'Growing up' chart if appropriate with YP, when asking:

When people talk about growing up and becoming an adult they often mean things like:

Show List

- Travelling about by yourself
- Doing different things in your spare time
- Going out with friends or by yourself
- Having a boyfriend or girlfriend
- Earning a bit of money
- Sorting out your own money (having your own bank account)
- Moving away from home or living with new people

What Doing and Feelings

4. Now you're older, have you started doing any of these things?

Probe What things

5. Do you like doing (new thing)?

Probe Why and how much/why not

Planning and Support

4. Who has helped you to do (new thing)?

Probe Who – family, friends, professionals

5. How has [name] helped you?

Probe If helpful and what's been most helpful
[If would like more help]

6. What other new things [show list card] would you like to do now?

Probe What and why
What's stopping them

Future Aspirations

3. In five years time, when you're (insert age), what other new things would you like to be doing?

Probe What and why
Any help needed – what sort and who helping

L4 Young person topic guide post-transition

In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Post-school Leaving YP Topic Guide

A. Introduction

NB: Complete the 'All about Me' chart if appropriate with YP, when asking:

1. What things have changed in your life since leaving school?

Show List College/employment
Friends
Things I do in my free/spare time
Doing more 'grown up things', doing things independently
People who help me, professionals I see

2. What things do you think will or might be different in the future?

Show List College/employment
Friends
Things I do in my free/spare time
Doing more 'grown up things', doing things independently
People who help me, professionals I see

B. Moving on from school

NB: Complete the 'Moving on from school – leaving X' chart if appropriate, when asking:

What Doing

1. You're now doing Y (college/work/other), was this what you wanted to do when you left school?

If wanted, probe Place they wanted to go to, the course/thing they wanted to do

If not wanted, probe What wanted to do, what stopped them doing it
If someone else chose

2. Was anything else suggested that you could have done?

Probe What and why not doing

Leaving School – Planning, Support and Feelings

1. Who helped you plan to leave X (school) and go to Y (college/work/other)?

[Help from professionals, family, friends, such as giving you information, organising visits to/spending time at college/work, helping you talk to people at college/work]

Probe Who, level and type of support
 What they did/help given
 If helpful and what was most helpful
 If wanted more help (what)
 If felt more help could have been given

2. Leaving school can be a busy time with lots of things happening, did you enjoy making plans to leave X (school) and go to Y (college/work/other)?

Probe What/what didn't enjoy (why)

3. Do you think making plans was helpful?

Probe Why/why not helpful

4. Looking back is there anything you miss about X (school)?

Probe What and why

5. Is there anything you don't miss?

Probe What and why

6. Did you have any worries/concerns about leaving X (school)

Probe What and why

7. Did you talk to anyone about this? [Such as school staff, family, friends, professionals]

If talked, probe Who and what suggested/did/help given
 If helpful and what was most helpful
 If wanted more help (what)

If didn't talk, probe Why not

After School – Support and Feelings

1. Now you've moved onto Y (college/work/other), what are you enjoying/is good about Y (college/work/other)?

Probe What and why

2. **Before you started at Y (college/work/other), was there anything you weren't looking forward to/were worried about?**

Probe What and why

3. **Did you talk to anyone about this? [Such as family, friends, professionals]**

If did talk, probe What suggested/did/help given
If helpful and what was most helpful
If wanted more help (what)

If didn't talk, probe Why not

4. **Has this worked out OK?**

Probe *Why/why not*

C. Services That Help Me

NB: Complete the 'Services that help me' chart if appropriate with YP, whilst asking:

Lots of different people help YP, such as:

Show List Social workers
Doctors
Psychologists
Community nurses
Counsellors
Speech and language therapists

Some YP also go to special clinics or centres to talk about your autism

Changes

1. **When you were at X (school), did any of these people help you or did you go to any special clinics/centres to talk about your autism?**

Probe Who saw or visited

2. **Now you've left school and become more 'grown up', do you still see (name of person) or visit (name of clinic/centre)?**

3. **Do you see any new people?**

Probe Who

Moving to New Services - Planning, Support and Feelings

NB: If YP has moved to new services, ask:

1. **How did you first meet Y (name of new professional)?**
Probe When and who else present (old professional, family etc)

2. **Did you talk to anyone about moving to Y (new professional)?**
Probe Who talked to
Was it helpful and what was most helpful
If wanted more help

3. **Looking back is there anything you miss about not seeing X (name of old professional) or going to (name of clinic/centre)?**
Probe What and why

4. **Is there anything you don't miss?**
Probe What and why

5. **Did you have any worries or concerns about leaving X (name of old professional) and moving to Y (name of new professional)?**
Probe What and why

6. **Did you talk to X (name of old professional) or anyone else about this?**
If talked, probe Who and what suggested/did/help given
If helpful, what was most helpful
Could X (name of old professional) have helped more (how)

If didn't talk, probe Why not

7. **Do you like Y (name of new professional)?**
Probe What likes/doesn't like (why)

8. **Do you think Y (name of new professional) is better than X (name of old professional)?**
Probe Why/why not

Future

NB: Ask all YP

1. **In the future, do you think you'll continue to see (name of professional/service)?**
Probe For how long
How YP feels about this

D. Growing Up

NB: Complete the 'Growing up' chart if appropriate with YP, when asking:

When people talk about growing up and becoming an adult they often mean things like:

Show List

- Travelling about by yourself
- Doing different things in your spare time
- Going out with friends or by yourself
- Having a boyfriend or girlfriend
- Earning a bit of money
- Sorting out your own money (having your own bank account)
- Moving away from home or living with new people

What Doing and Feelings

1. Now you're older, have you started doing any of these things?

Probe What

2. Are you enjoying doing (new thing)?

Probe Why and how much, why not

3. Was it difficult/hard to start doing (new thing)?

Probe Why/why not

Planning and Support

1. Has anyone helped you do (new thing)? [Such as family, friends or professionals]

Probe Who, level and type of support
What they've been doing/helping with
If helpful and what's been most helpful
If would like more help (what)

2. Are you still getting any help with (new thing)/learning to do (new thing)?

Probe Level and type of help still getting
If happy with this
If helpful and what's been most helpful
If would like to continue getting help (what)

3. Are there any things [show list card] that you're not doing now but you'd like to do now?

Probe What and why
What's stopping them

Future Aspirations

- 1. We've talked about new things that you're now doing or want to do now; in the future, what other sorts of things [show list card] would you like to do/do more of?**

Probe What and why

- 2. In five years time, when you're (insert age), do you think you'll be doing/have (new thing)**

Probe Why thinks will/will not be doing/have

If thinks will need any help

If help needed, who will help and how

In Transition: Young People with Autistic Spectrum Conditions Growing Up and Planning for the Future

Post-school Leaving YP – Simpler Topic Guide

A. Introduction

NB: Complete the 'All about Me' chart if appropriate with YP, when asking:

1. After you left school, what things changed in your life?

Show List College/employment
Friends
Things I do in my free/spare time
Doing more 'grown up things', doing things independently
People who help me, professionals I see

2. In the future, what things do you think will change?

Show List College/employment
Friends
Things I do in my free/spare time
Doing more 'grown up things', doing things independently
People who help me, professionals I see

B. Moving on from school

NB: Complete the 'Moving on from school – leaving X' chart if appropriate, when asking:

What Doing

1. You now do Y (college/work/other), was this what you wanted to do when you left X (school)?

If wanted, probe Place they wanted to go to, course/thing they wanted to do

If not wanted, probe What wanted to do, what stopped them doing it
If someone else chose

Leaving School – Planning, Support and Feelings

- 1. Who helped you think about leaving X (school) and going to Y (college/work/other)?**
[Help from professionals, family, friends, such as giving information, organising visits to/spending time at college/work, helping YP talk to people at college/work]

Probe Who and what help given
If helpful and what was most helpful
[If wanted more help]

- 2. What things do you miss about X (school)?**

Probe What and why

- 3. What things don't you miss about X (school)?**

Probe What and why

- 4. Did you have any worries about leaving X (school)?**

Probe What and why

- 5. Did you talk to anyone about [insert worries]?** *[Such as school staff, family, friends, professionals]*

If talked, probe Who and what suggested/did/help given
If helpful and what was most helpful
[If wanted more help]

If didn't talk, probe Why not

After School – Support and Feelings

- 1. What do you like about going to Y (college/work/other)?**

Probe What and why

- 2. Before you went to Y (college/work/other), were you worried about anything?**

Probe What and why

- 3. Did you talk to anyone about this?** *[Such as family, friends, professionals]*

If did talk, probe Who and what suggested/did/help given
If helpful and what was most helpful
[If wanted more help]

If didn't talk, probe Why not

4. **Has this worked out OK?**
Probe why/why not

C. Services That Help Me

NB: Complete the 'Services that help me' chart if appropriate with YP, whilst asking:

Lots of different people help YP, such as:

Show List Social workers
Doctors
Psychologists or counsellors
Community nurses

Some YP also go to special clinics or centres to talk about autism

Changes

1. **When you were at X (school), did any of these people help you or did you go to any special clinics/centres to talk about autism?**
Probe Who saw or visited
2. **Do you still see (name of person) or visit (name of clinic/centre)?**
3. **Do you see any new people?**
Probe Who

Moving to New Services - Planning, Support and Feelings

NB: If YP has moved to new services, ask:

1. **Who helped you meet Y (name of new professional)?**
Probe Who (old professional, family etc)
What did/help given
Was it helpful and what helped most
[If wanted more help]
2. **Do you miss not seeing X (name of old professional) or going to (name of clinic/centre)?**
Probe What misses and why
3. **Is there anything you don't miss?**
Probe What and why

4. **Were you worried about leaving X (name of old professional) and having Y (name of new professional) as your new (SW/Dr etc)?**

Probe What and why

5. **Did you talk to anyone about this?**

If talked, probe Who and what suggested/did/help given
If helpful and what most helpful
[Could X (name) have helped more]

If didn't talk, probe Why not

6. **Do you like Y (name of new professional)?**

Probe What likes/doesn't like (why)

7. **Do you think Y (name of new professional) is better than X (old professional)?**

Probe Why/why not

D. Growing Up

NB: Complete the 'Growing up' chart if appropriate with YP, when asking:

When people talk about growing up and becoming an adult they often mean things like:

Show List Travelling about by yourself
Doing different things in your spare time
Going out with friends or by yourself
Having a boyfriend or girlfriend
Earning a bit of money
Sorting out your own money (having your own bank account)
Moving away from home or living with new people

What Doing and Feelings

1. **Now you're older, have you started doing any of these things?**

Probe What things

2. **Do you like doing (new thing)?**

Probe Why and how much, why not

Planning and Support

1. **Who has helped you to do (new thing)?**

Probe Who – family, friends, professionals

2. How has (name) helped you?

Probe If helpful and what's been most helpful
[If would like more help]

3. What other new things [show list card] would you like to do now?

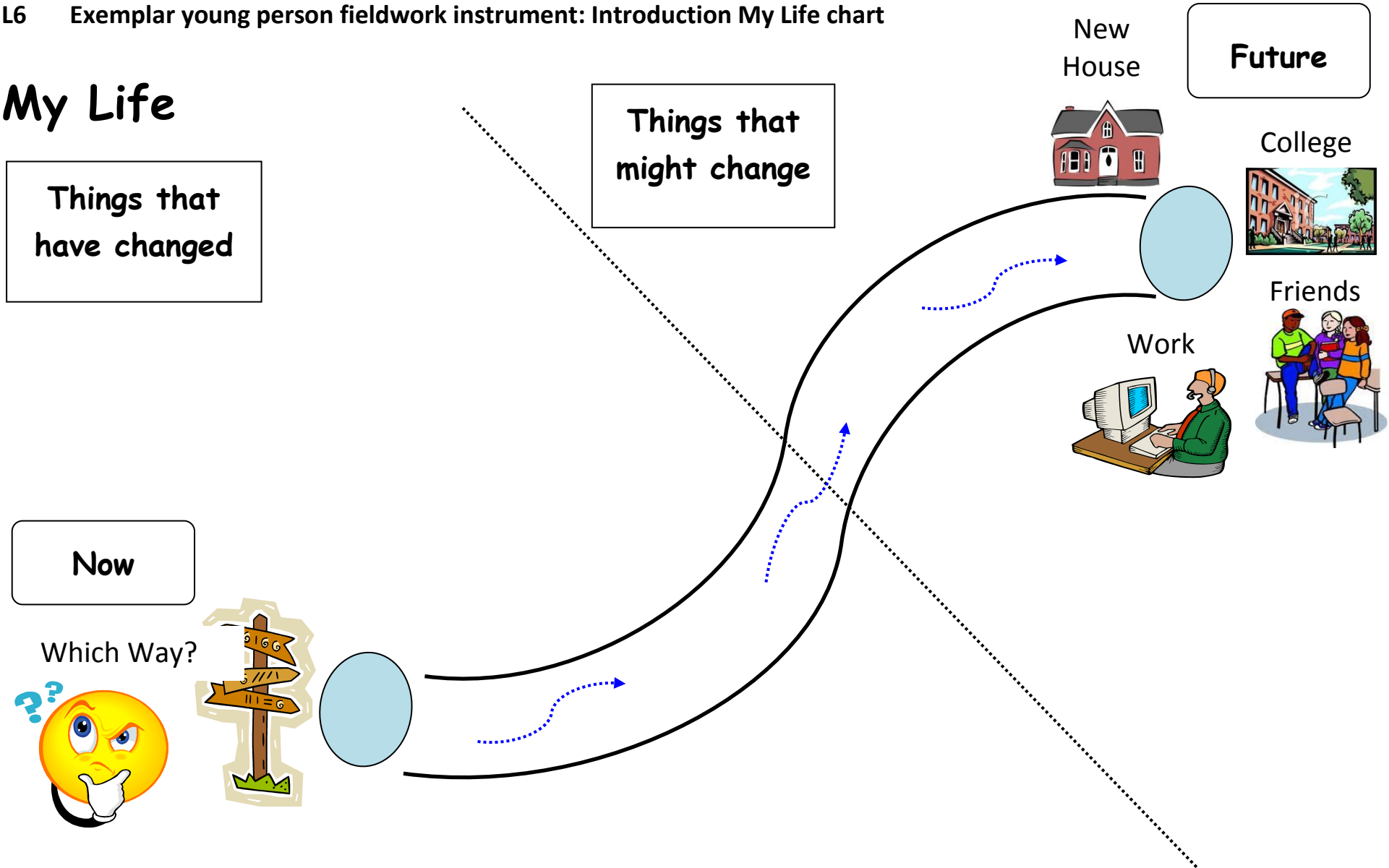
Probe What and why
What's stopping them

Future Aspirations

1. In five years time, when you're (insert age), what other new things would you like to be doing?

Probe What and why
Any help needed – what sort and who helping

My Life



L7 Exemplar young person fieldwork instrument: Moving on from School chart

Good Things



Now I've left school

College



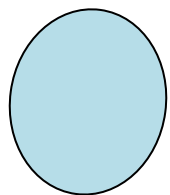
Work



Preparing to leave school



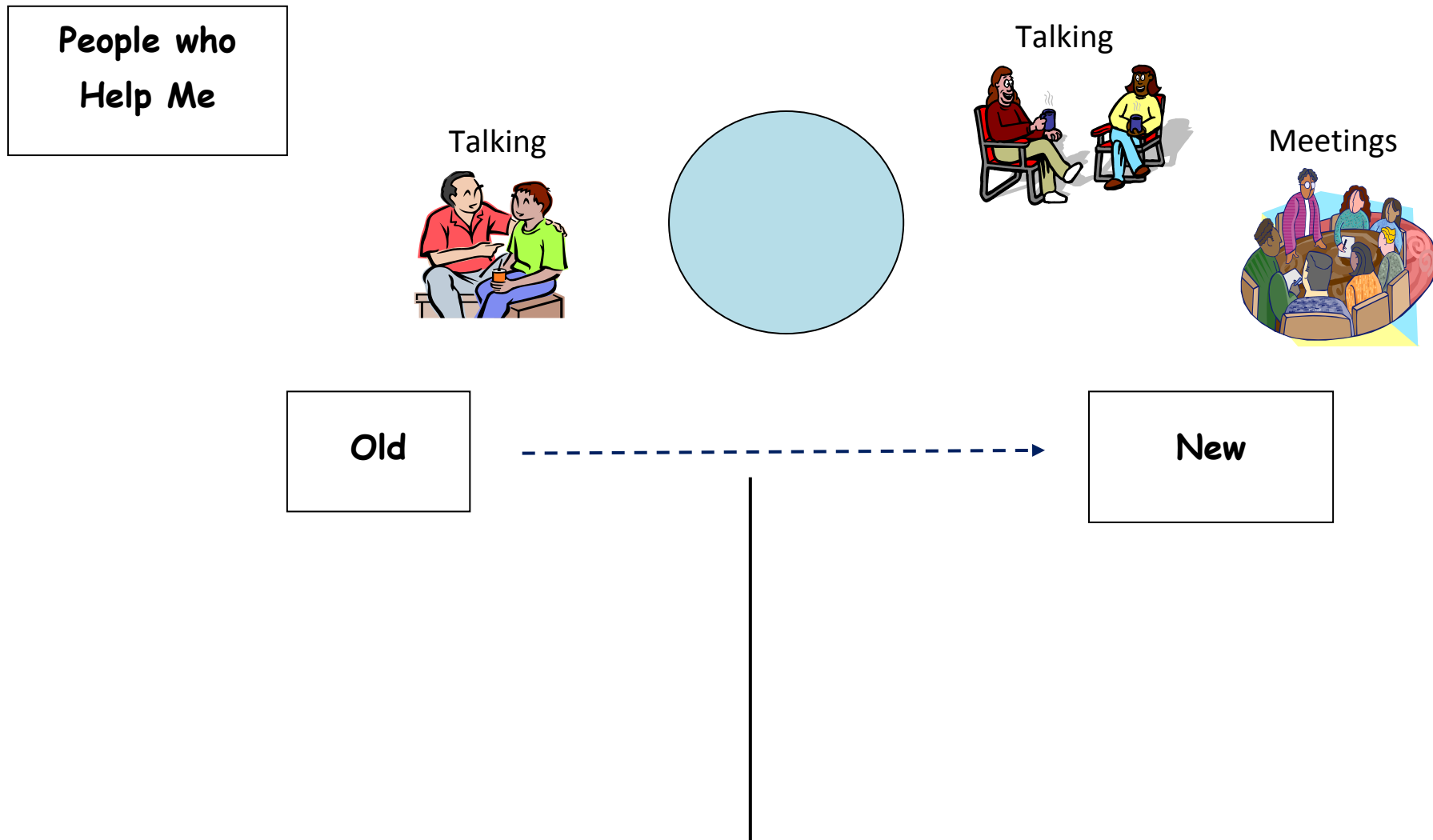
Which Way?



Not So Good Things



L8 Exemplar young person fieldwork instrument: Services that Help Me chart



Growing Up

Things I want
to do in the
future

New things
I'm doing

