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Α. AUTISM INTERVENTION PACKAGES DIRECTLY WITH CHILD

In this section we are interested in any autism intervention packages you have received other than as part of the study. We are only interested in packages with a minimum of 4 sessions in the last 6 months .

1. Have you used any autism intervention packages other than as part of this study in the last <u>6 months</u>?

Yes	1
No	2

a. If yes, which of the following services have you used in the last 6 months?

	Average number of sessions	Average duration of session
ABA/EIBI (intensive behavioural intervention))		
Son-Rise Programme		
Relationship Development Intervention		
Social skills programme (directly with child)		
Other intensive home-based autism treatment package. Please give details:		

SENITA

B AUTISM-RELATED PARENT TRAINING

In this section we are interested in any autism-related parent focused training <u>other than</u> as part of the study. If you have attended any courses, workshops or training related to your child's autism, please indicate the number of sessions and the average duration of the sessions. We are only interested in courses, workshops or training with a minimum of 4 sessions in the last 6 months .

2. Have you used any autism-related parent training <u>other than</u> as part of this study <u>in the</u> <u>last 6 months</u>?

Yes	1
No	2

a. If yes, which of the following services have you used in the last 6 months?

	Average number of <u>sessions</u>	Average duration of session
Parent-mediated communication programme (Include only group sessions)		
EarlyBird/Help		
Behaviour management training		
Alternative and augmentative systems, including PECS, sign language (e.g. BSL, Makaton)		
Other autism-related parent , please give details:		
Other autism-related parent training, please give details:		

Your unique serial number

Section C SERVICE USE BY THE CHLD

EDUCATION

3. What type of education provision (e.g. school/ flexi school) does/did [child's name] *usually* receive? Indicate all that apply for the last school year.

If [child's name] has recently been permanently/temporarily excluded from school or does

not attend school please tick box \square and **indicate their last usual** type(s) of formal education received prior to the permanently/temporarily exclusion or other reasons.

	Part-time	Full time	No. of terms in the last school year	Fees paid Yes/No
Mainstream day school/college				
Special education unit in mainstream school				
Special residential school				
Special day school				
Pupil Referral Unit (PRU)				
Home education/school				
Other (please specify)				

4. Did [child's name] have any help with education in the last 6 months?

Yes	1
No	2

a. **If yes**, please state for the support shown in the table below the number of hours each week <u>in the last 6 months?</u>

	No	Yes	No. hours each week on average <u>in</u> <u>the last 6 months</u>
Individual tuition at home			

SENITA	Your unique serial number
<u>1:1</u> support in school (e.g. Learning Support	
Assistant [LSA]) Group support in school (e.g. small group work with a LSA).	h
Other support 1 (please specify)	
Other support 2 (please specify)	·
No additional help <u>in the last 6 months</u>	

5. Did [child's name] see any of the following people in pre-school, primary school <u>in the last 6 months</u>?

	No	Yes	No. of contacts on average <u>in the last</u> <u>6 months</u>	Duration of contact on average <u>in</u> <u>the last 6</u> <u>months</u>
School nurse				
Educational psychologist				
Counsellor/learning mentor				
SENCO				
Other support 1 (please specify)				
Other support 2 (please specify)				

SENITA	Your unique serial number
6. Does [child's name] have a 'Stateme Health Care Plan? Yes No	ent of Special Educational Needs' or 'Education and 1 2 3
 7. Has [child's name] been excluded fr Yes No 8. Has [child's name] been excluded fr 	1 If yes, how many days in the last 6 months?
Yes	1 If yes, how many days in the last 6 months?

HEALTH AND SOCIAL CARE

9. Has [child's name] made contact with any health and social care services <u>in the last 6</u> <u>months</u>?

Yes	1
No	2

a. If yes, which of the following services has [child's name] used in the last 6 months?

	No	Yes	If yes, how many times on average <u>in the</u> <u>last 6 months</u> ?
GP (visits or calls)			
Practice nurse (visits)			
SLT (contacts)			
Community paediatrician (contacts)			
CAMHS psychiatrist (local service) (contacts)			
Clinical psychologist (contacts)			
Counsellor/Psychotherapist (contacts)			

Your	unique	e serial	number
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Behaviour support team member (contacts)	
Social worker (contacts)	
Respite care (sessions)	
Outreach worker/ Family support worker (contacts)	
Inpatient admission – mental health (overnight	
stay)	
Inpatient admission - physical health (overnight	
stay)	
Accident and emergency (not requiring a stay in	
hospital)	
Accident and emergency (<i>requiring a stay in</i>	
hospital)	
Other (e.g. Occupational therapist,	
Physiotherapist, Dentist, Dietician, Optician,	
alternative therapies) (please specify)	
Other 2 (please	
specify)	
Other 3 (please	
specify)	

POLICE AND YOUTH JUSTICE SYSTEM

10. Has [child's name] been involved with the police or the youth justice system in the last 12 months? (Tick all that apply).

Yes, as a victim	1	Ask Q11 then skip to section D
Yes, as a witness	2	Skip to section D.
Yes, as a suspect (e.g. someone thought they might have done something wrong)	3	If this box is ticked, do not skip to section D. Even if other boxes are ticked above.
No contact	4	Skip to section D.

1. Has [child's name] appeared in court in the last 12 Yes No 2 . If yes, how many times in the last 12 months? 2. Has [child's name] had formal police cautions in the Yes 1 No 2 . If yes, how many times in the last 12 months? 1 No 2 . If yes, how many times in the last 12 months? . If yes, how many times in the last 12 months? . If yes, how many times in the last 12 months?	
No	
. If yes, how many times in the last 12 months? 2. Has [child's name] had formal police cautions in the Yes 1 No 2 If no, . If yes , how many times <u>in the last 12 months</u> ?	
 2. Has [child's name] had formal police cautions in the Yes	
Yes 1 No 2 If no, I I J I I J I I J J I I J D	
No If yes , how many times <u>in the last 12 months</u> ?	e last 12 months?
. If yes , how many times <u>in the last 12 months</u> ?	
	skip to Section
. Reasons for cautions? (please specify)	
ection D CAREGIVER HEALTH	

13. Do you think that [child's name] behaviour has affected your health in the last 6 months?

Yes..... 1 No..... 2

a. If yes, which of the following services have you used in the last 6 months?

			If yes, how
	No	Yes	many times on
	No	165	average <u>in the</u>
			last 6 months?
GP (visits or calls)			
Practice nurse (visits)			
Counsellor (<i>visits</i>)			
Self-help or support group (visits)			
Alternative therapist (shiatsu etc.) (visits)			
Telephone help-line (calls)			
Hospital outpatient clinic (<i>appointments</i>)			

SENITA	Your unique serial number
Accident and emergency (<i>contact, not requiring admission</i>)	
Accident and emergency (<i>contacts requiring admission</i>)	
Inpatient admission (<i>nights</i>)	
Other 1 (not stated above, please secify)	
Other 2 (not stated above, please secify)	
Other 3 (not stated above, please secify)	

Section E SIBLING HEALTH

14. Do you think that [child's name] behaviour has led to their siblings needing additional mental or physical health-related support, e.g. counselling, <u>in the last 6 months</u>?

Yes	1
No	2

a. **If yes**, please specify in the table below:

	How many times on average <u>in the last 6</u> <u>months</u>
Counsellor	
Other support (please specify)	
Other support (please specify)	

Section F OUT-OF-POCKET EXPENSES

In this section we are asking your help in telling us about any **out-of-pocket expenses** you have incurred to provide for the needs of your child. Out-of-pocket expenses are defined as any payments made from personal funds to cover treatment, support and care as a result of autism and mental health problems. These payments represent <u>money paid by you over and above</u> any contributions from statutory services (such as benefit payments) and voluntary organisation.

15. Have you incurred expenses as a result of [child's name] behaviour in the last 6 months?

Yes	1
No	2

a. If yes, please fill in the table below

	Total out-of-pocket expenses in an average week <u>in the last 6</u> <u>months</u>
Adaptation/alterations to home (e.g. sensory room)	
Expenses for special toys or equipment	
Replacement cost or repair of damage to toys and furniture	
Expenses for medication	
Extra help expenses (e.g. child care) (please specify)	
Expenses for special education (please specify) (e.g. private school fees, tutor)	
Expenses for therapy (please specify)	
Expenses for special activities (please specify)	
Travel expenses to treatment or assessment	
Other (please describe) Include additional specifications mentioned above and any other not included in the list	

Your unique serial number

Other (please describe) Include additional specifications mentioned above and any other not included in the list	
Other (please describe) Include additional specifications mentioned above and any other not included in the list	

Section G UNPAID SUPPORT

Note to Researcher: Please ensure that the data in this section is filled in by the **main unpaid caregiver**. If the respondent is retired or not currently working, record most recent main paid job and occupation.

16. Is the main caregiver currently unemployed **and** has never been in paid employment?

Yes	1
No	2

Questions 16-23 refer to **main caregiver/parent's** current or last main job and occupation. **If the respondent is retired or not currently working, record most recent main paid job /occupation.**

17. Employee or self-employed:

Do/did you work as an employee or are/were you self-employed?

Employee

Self-employed with employees

Self-employed/freelance without employees

Go to 20

18. Number of employees:

For employees: How many people work/worked for your employer at the place where you work/worked?

For self-employed: How many people do/did you employ?

1-24	
25 or more	

19. Supervisory status:

Do/did you supervise any other employees? (A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis).

SENITA	Your unique serial number					
Yes 1						
No 2						
20. Occupation:						
Tick one box to show which best describes the caregiver/parent is not working now, ask him/ their last job.			-			
Modern professional occupations such as: physiotherapist – social worker – welfare musician – police officer (sergeant or abo	officer –	artist–		r		
Clerical and intermediate occupations suc personal assistant – clerical worker – offic agent – nursing auxiliary – nursery nurse						
Senior managers or administrators (usual planning, organising and co-ordinating we such as: finance manager – chief executiv	ork, and f					
Technical and craft occupations such as: – inspector – plumber – printer – tool ma gardener – train driver				er		
Semi-routine manual and service occupat worker — machine operative — security gu worker — catering assistant — receptionist	ard – car	etaker	– farm			
Routine manual and service occupations s van driver – cleaner – porter – packer – s messenger – labourer – waiter/waitress –	ewing ma	achinist				
Middle or junior managers such as: office manager – bank manager – restaurant m manager – publican						
Traditional professional occupations such solicitor – medical practitioner – scientist engineer						

- 21. What is your approximate gross pay per year (before tax) for your current or most recent employment?

1	Under £5,000	8	£35001-£40000
2	£5001 - £10000	9	£40001-£45000
3	£10001 - £15000	10	£45001-£50000
4	£15001-£20000	11	£50001-£75000
5	£20001-£25000	12	£75001-£100000
6	£25001-£30000	13	£100001 plus
7	£30001-£35000		

22. How many hours do/did your employer expect you to work in a typical 7-day week for your current or most recent employment? If it varies, estimate the average. If more than 97 enter 97.

How many hours?

23. How many half days have you been absent from work due to [child's name] condition <u>in</u> <u>the last 6 months?</u>

How many half days <u>in the last 6</u> <u>months</u>?

24. Have you taken time off work due to [child's name] condition in the last 6 months?

	1	If yes, how many half days <u>in the</u> last 6 months?	
	2		
to [ch	ild′s n	ame] condition <u>in the last 6 m</u>	onths?
	1	If yes, how many half days in the last 6 months?	
	2		
	e to [ch	1	1 last 6 months? 2 e to [child's name] condition in the last 6 months? 1 If yes, how many half days in the last 6 months?

26. In your opinion, has [child's name]'s condition affected your employment/career prospects? Yes		SENITA	Your unique serial number
prospects? Yes			
No			ition affected your employment/career
If yes, please state how?		Yes	
27. In your opinion, has [child's name] condition affected your family/romantic relationshi Yes		No 2	
27. In your opinion, has [child's name] condition affected your family/romantic relationshi Yes		If yes, please state how?	
Yes 1 No 2 If yes, please state how? 1 28. In your opinion, are there any services and support you are not getting now, you woulkike to receive? Yes 1 No 2 If yes, please state 1 No 2 If yes, please state 1 No 2 If yes, please state 1 No			
No	27. In y	your opinion, has [child's name] condition	on affected your family/romantic relationshi
If yes, please state how?		Yes	
28. In your opinion, are there any services and support you are not getting now, you wou like to receive? Yes		No 2	
28. In your opinion, are there any services and support you are not getting now, you wou like to receive? Yes		If yes, please state how?	
You have come to the end of the form		e to receive? Yes	
You have come to the end of the form		If yes, please state	
You have come to the end of the form			