

Summary

Background Information

- In total, **721 adults responded** to either the Support Services questionnaire or the Health and Education questionnaire. Overall, **88%** of respondents said they were **resident in the UK**.
- A third of the respondents said their child was aged 13-15, with around a fifth saying their child was aged under 10, 10-12 and 16-18 respectively. Around a tenth of respondents said their child was aged 19 or older. The majority of children were said to be male (80%).

Diagnosis and Information

- **Over 80%** of respondents said their child had been **formally diagnosed**. Over half said this had taken place when their child was aged under 10.
- **90%** said they thought their child had **been given the correct diagnosis**. However, **two-thirds** of respondents said the process of diagnosis had taken **one year or longer** and a **quarter** said it had taken **5 or more years**. **Over half** of the respondents said the support they had received during the process of diagnosis had been **'poor'** or **'very poor'** and over half said the **information** they had been given about Asperger's had been **'poor'** or **'very poor'**.

Professional Services

- **Under a fifth** of the respondents said the **levels of understanding** demonstrated by various agencies was **'very helpful'**. The understanding demonstrated by **education** and **social services** was said to be **'very poor'** by **more than a third** of respondents.
- Similarly, **under a fifth** of the respondents said the **help** they had received from various agencies was **'very good'**. Again, the help provided by **education** and **social services** was said to be actually **'unhelpful'** by **half or more than half** of the respondents.
- Respondents were equally negative about the extent to which different agencies worked together to help their child. **Only 2%** said the agencies had worked together **'Very well'** and **38%** said they **hadn't worked together at all**.
- **A third (38%)** said there was a **team of professionals** centred around their child, aiming to meet their child's needs. **Two-thirds (64%)** said the team worked **'Very well'** or **'Quite well'** together, compared to **21%** of respondents saying the different agencies in general had worked well together.

Educational Provision

- **38%** said their child attended a large, inclusive school with LSA support or another type of provision. However, only **9%** and **16%** respectively also said that they thought these types of provision most suited their child's needs. Although **27%** of respondents said they thought a special Asperger's needs school would best suit their child's needs, **only 4%** said their child currently attended this type of provision.
- The most common barriers to obtaining a suitable education were the availability of appropriate schools locally (42%), the statementing process (32%) and obtaining a correct diagnosis (30%).
- **35%** said their child had spent **significant amounts of time out of education.**
- **Under a fifth** of respondents said they were **'Very satisfied'** with their child's **education provision** and the same proportion of respondents said they were 'Very unsatisfied'. Just over a third said they were 'Satisfied' (39%).
- Under 10% said they thought their child had 'completely' received an adequate education or had reached their full potential. **A quarter** of the respondents (28%) said they **did not think their child had received an adequate education** and **half** of the respondents (51%) said they **did not think their child had reached their full potential.**

Personal Concerns in Education

- **87%** of respondents said they **had concerns about future educational provision** for their child.
- **Half** of the respondents (53%) said they thought **their child had not been happy throughout their education.** Only 18% said they thought their child had been happy.
- Most respondents said their children had **experienced bullying** at school, due to having Asperger's / Autism. **Only 7%** said their child had **never** experienced bullying and **42%** said their child experienced bullying **'often'**.
- **Only 4%** said their child's **school had dealt with the bullying 'Very well'** and **31%** said **'Not at all well'**, with a further **40%** saying **'Not very well'**.
- Of 203 respondents who said their child had sensory issues that might affect their ability to function in a school setting,¹ **over half (60%) said their child's needs had not been met.**

¹ This is 67% of 305 responding overall.

Mental and Emotional Wellbeing

- **91%** of respondents said they **had concerns about their child's mental or emotional wellbeing**, of whom 48% said 'quite often'. **Only 10%** said they were **able to access as much help as they needed** for their concerns.
- **92%** of respondents said that caring for a child with Asperger's syndrome or Autism also **had an impact on their own mental or emotional wellbeing**. Of these, **only 20%** said they were **able to access the help they needed**.
- 52 respondents said their child had been prescribed antipsychotic drugs and 78 respondents said their child had received psychiatric care.

Finances and Accommodation

- **96%** said they were **still financially supporting their child** (aged over 18).
- 68% said they had applied for the Disability Living Allowance (DLA). The most common reason given for not applying for the DLA was not knowing about it (given by a third).
- **86%** said they had found it **'difficult' or 'very difficult' to fill in the DLA forms**. In addition, **nearly two-thirds** of respondents said they had **not found the DLA questions useful or relevant** for assessing their child's current situation or needs.

Background Information

Two questionnaires were available for respondents to choose to complete: one relating to Support Services and one relating to Health and Education. In total, 721 adults responded to either the Support Services questionnaire or the Health and Education questionnaire, with a fairly even number of respondents for each (369 for the Support Services questionnaire and 352 for the Health and Education questionnaire).

It is not clear how many people answered both questionnaires, as this was not directly measured. When asked to provide an email address for follow-up information, 70 respondents gave the same email address for both questionnaires, so a minimum of 70 respondents can be said to have answered both questionnaires. However, this is not a definitive number as the option to provide an email address was voluntary and a large number of respondents chose not to do so.

Of the 721 respondents across both questionnaires, the majority said they were resident in the UK (88%). Individually, 87% of the Support Services questionnaire and 89% of the Health and Education questionnaire said they were UK residents. Other respondents resided in the USA and Australia.

Table: Country of residence (Support Services and Health / Education questionnaires)

	Support Services		Health & Education		Total	
	n	%	n	%	n	%
UK	322	87%	314	89%	636	88%
USA	28	8%	27	8%	55	8%
Australia	7	2%	5	1%	12	2%
Other	12	3%	6	2%	18	2%
Total	369	100%	352	100%	721	100%

Of 719 respondents across both questionnaires, there was a fairly even spread of age ranges, with most saying their child was aged 13-15 (31%) and with around a fifth saying their child aged under 10, 10-12 and 16-18 respectively. Around a tenth of respondents said their child was aged 19 or older. This proportion is also reflected in the respondents associated with each of the questionnaires (see table below).

Table: Age of child (Support Services and Health / Education questionnaires)

	Support Services		Health & Education		Total	
	n	%	n	%	n	%
Under 10	62	17%	56	16%	118	16%
10 to 12	75	20%	75	21%	150	21%
13 to 15	109	30%	113	32%	222	31%
16 to 18	79	22%	76	22%	155	22%
19 or older	42	11%	32	9%	74	10%
Total	367	100%	352	100%	719	100%

The majority of respondents across both questionnaires said their child was male (80% of 724 responding).

Of 369 respondents for the Support Services questionnaire and 355 respondents for the Health and Education questionnaire:

- **80%** of the Support Services questionnaire said their child was male
- **20%** of the Support Services questionnaire said their child was female
- **81%** of the Health and Education questionnaire said their child was male
- **19%** of the Health and Education questionnaire said their child was female

This distribution remained fairly consistent across the age ranges, with between 72-90% of the different age groups for the two questionnaires being male (see table).

Table: Age of child by gender (Support Services and Health / Education questionnaires)

	Support Services		Health & Education		Total
	Female	Male	Female	Male	
Under 10	10%	90%	14%	86%	100%
10 to 12	21%	79%	12%	88%	100%
13 to 15	20%	80%	27%	73%	100%
16 to 18	28%	72%	22%	78%	100%
19 or older	20%	80%	13%	88%	100%
Total	20%	80%	20%	80%	100%

Diagnosis and Information

Respondents to both questionnaires were asked if their child had been formally diagnosed with Asperger's Syndrome or another form of Autism and at what age. Of 720 responding across both questionnaires, most said their child had been diagnosed with Asperger's Syndrome (72%) and a further 13% said their child had been diagnosed with Autism. Just over a tenth (15%) said their child had not been formally diagnosed.

Table: Has your child been formally diagnosed with Asperger's Syndrome or another form of Autism?

	Support Services		Health & Education		Total	
	n	%	n	%	n	%
Yes (Asperger's Syndrome)	266	72%	253	72%	519	72%
Yes (another form of Autism)	50	14%	41	12%	91	13%
No (not formally diagnosed)	52	14%	58	16%	110	15%
Total	368	100%	352	100%	720	100%

Of the 604 respondents across both questionnaires who said their child had received a formal diagnosis, over half said this had taken place when their child was aged under 10 (58%). A further 22% said their child had been aged 10-12 and 17% said their child had been aged 13-15. Only 3% said their child had been aged 16 or older.

Table: At what age was your child diagnosed with Asperger's Syndrome or Autism?

	Support Services		Health & Education		Total	
	n	%	n	%	n	%
Under 10	181	58%	172	59%	353	58%
10 to 12	69	22%	61	21%	130	22%
13 to 15	53	17%	47	16%	100	17%
16 to 18	8	3%	13	4%	21	3%
Total	311	100%	293	100%	604	100%

The respondents answering the Health and Education questionnaire alone were given follow-up questions in relation to the process of diagnoses. Of the 290 respondents answering the Health and Education questionnaire whose child had received a formal diagnosis, **90%** said they thought their child had been given the right diagnosis. In addition, the remaining **10%** said they were 'not sure' about the diagnosis, rather than giving a more definitive 'no' response.

Of the 261 respondents who said their child had been given what they considered to be the right diagnosis, **67%** said it had taken 1 year or longer to get the diagnosis. A **quarter** of the respondents said it had taken **5 or more years**.

Of 261 responding:²

- **3%** said it had taken under 1 month to get the diagnosis
- **7%** said it had taken 1-3 months to get the diagnosis
- **11%** said it had taken 4-6 months to get the diagnosis
- **8%** said it had taken 7-11 months to get the diagnosis
- **24%** said it had taken 1-2 years to get the diagnosis
- **17%** said it had taken 3-4 years to get the diagnosis
- **26%** said it had taken 5 or more years to get the diagnosis

In addition to most respondents describing long periods of time being taken to get what they considered to be the right diagnosis, it is also clear that throughout this process most respondents felt unsupported. When asked to rate the help and support they were given during the diagnosis process, **over half** of the respondents said '**poor**' or '**very poor**' (**58%**). Only 10% of the respondents said the help they had received was 'very good' (see table below).

A very similar proportion of respondents also described the information they had been given about Autism or Asperger's Syndrome in general as good or poor. **Over half** described the information they had been given as '**poor**' or '**very poor**' (**55%**) and only 10% described the information as 'very good'.

Table: How would you rate the help and support you were given during diagnosis / the information you have been given about Autism or Asperger's Syndrome (overall)?

	Help and Support during diagnosis		Information provided overall	
	n	%	n	%
Very good	29	10%	35	10%
Good	91	32%	120	35%
Poor	114	40%	135	39%
Very poor	52	18%	55	16%
Total	286	100%	345	100%

² 3% gave an 'other' response.

Professional Services

Professional Services: Knowledge and Awareness

Respondents answering the Support Services questionnaire were asked to rate the level of understanding of their child's Asperger's or Autism demonstrated by a range of agencies.

A number of respondents said they had *not* been in contact with some of the agencies listed, most commonly the police / criminal justice organisations (83%), but also social services (58%), voluntary organisations (30%) or mental health organisations (23%).

Of 336 responding:

- 7% said they had no contact with health professionals
- 23% said they had no contact with mental health professionals
- 4% said they had no contact with education professionals
- 58% said they had no contact with social services
- 83% said they had no contact with police / criminal justice
- 30% said they had no contact with voluntary organisations

The respondents who said they had been in contact with the agencies listed gave different ratings in relation to the level of understanding displayed by the different agencies. In most cases, **under a fifth** of respondents rated any of the agencies as 'very good', with the exception of mental health services or voluntary organisations. However, around a quarter of respondents rated all of the agencies as 'good'.

Nevertheless, nearly all agencies were rated as 'very poor' by around a fifth or more of the respondents. The level of understanding demonstrated by **education, social services** and **police** were rated as 'very poor' by 35%, 46% and 44% of respondents respectively.

Table: How would you describe the level of understanding of your child's Asperger's / Autism demonstrated by each of these (listed) agencies?

	Very good	Good	Poor	Very poor	Total	
	%	%	%	%	n	%
Health	13	37	32	18	271	100
Mental Health	28	32	24	16	223	100
Education	11	26	28	35	282	100
Social Services	2	24	27	46	121	100
Police	6	22	28	44	50	100
Voluntary	36	50	10	4	205	100

A negative assessment of levels of understanding is of particular importance for education services, as education was one of two services (along with health) that the majority of respondents had contact with (96%). As a service provider most commonly in contact with parents, education could be seen to be a principal source of help for people seeking support and information for Asperger's Syndrome or Autism. However, a large number of respondents indicated that the education services they were in contact with had not demonstrated a satisfactory level of understanding (63% described it as 'poor' or 'very poor'). Health services, which 93%

of respondents were in contact with, were also rated as 'poor' or 'very poor' by 50% of respondents.³

Professional Services: Help and Support

Respondents answering the Support Services questionnaire were also asked to rate the help and support they had received from a range of agencies.

Again, a similar proportion of the respondents said they had *not* been in contact with some of the agencies listed.

Of 336 responding:

- **10%** said they had no contact with health professionals
- **25%** said they had no contact with mental health professionals
- **5%** said they had no contact with education professionals
- **57%** said they had no contact with social services
- **85%** said they had no contact with police / criminal justice
- **26%** said they had no contact with voluntary organisations

The respondents who said they had been in contact with the agencies listed gave different ratings of the help they received from the different agencies. As was also found for professional levels of understanding, in most cases, **a fifth or under a fifth** of respondents rated any of the agencies as '**very helpful**', with the exception of mental health services or voluntary organisations. However, again around a quarter or respondents rated all of the agencies as 'good'.

Nevertheless, nearly all agencies were rated as '**unhelpful**' by around **a third or more** of the respondents. The level of help received from **social services, police** and **education** were rated as '**unhelpful**' by **70%, 66%** and **49%** of respondents respectively. Again, this is of particular importance for services such as education and health, with 90% or more of the respondents saying they were in contact. **Nearly half** of the respondents said they found the help given by education or health '**unhelpful**'.

Table: How would you describe the help you have received from each of these (listed) agencies?

	Very helpful	Helpful	Unhelpful	Total	
	%	%	%	n	%
Health	10	46	44	283	100
Mental Health	20	41	39	236	100
Education	12	39	49	294	100
Social Services	4	26	70	133	100
Police	4	30	66	47	100
Voluntary	40	45	14	231	100

³ It should be noted that the services that fewer respondents were in contact with had a lower number of respondents rating the level of understanding demonstrated, so percentages should be viewed with caution.

Respondents were equally negative about the extent to which different agencies worked together to help their child. **Only 2%** said the agencies had worked together **'Very well'** and **38%** said they **hadn't worked together at all**.

Of 285 responding:

- **38%** said agencies hadn't worked together at all
- **41%** said 'Not at all well' or 'Not very well' (of which **14%** said 'Not at all well')
- **21%** said 'Very well' or 'Quite well' (of which only **2%** said 'very well')

Of 298 adults responding, only around **a third (38%)** said **there was a team of professionals centred around their child**, aiming to meet their child's needs. Those who said there was a team of professionals were more positive about the team of professionals working well together than the general responses relating to the agencies (above). Two-thirds (64%) said the team worked 'Very well' or 'Quite well' together, compared to 21% of respondents saying the different agencies had worked well together (above).

Of 113 adults who said there was a dedicated team of professionals:

- **19%** said they worked together 'Very well'
- **45%** said they worked together 'Quite well'
- **23%** said they worked together 'Not very well'
- **13%** said they worked together 'Not at all well'

Educational Provision

Educational Provision: Types of Provision

Respondents were asked to select from a list the type of educational provision they thought should be available. More than one response could be selected by each respondent. Respondents selected a diverse range of educational provision, with equal numbers selecting home schooling options, in-school options and flexible options. Although respondents most commonly selected 'Special Asperger needs school' (60%), only half the amount selected the more generic 'Special needs school' (30%). In addition, 60% also selected 'Flexible schooling'. Similarly, around half of respondents thought there should be home schooling with LEA support, but half also thought there should be special units attached to a school. Unsupported home schooling was selected by the fewest respondents, although a third still thought this type of provision should be available.

Of 330 responding:

- 60% said 'Special Asperger needs school'
- 60% said 'Flexible schooling'
- 52% said 'Home schooling with LEA supporting tutoring/resources'
- 52% said 'Special units attached to a school'
- 38% said 'Large, inclusive school with LSA support'
- 35% said 'Inclusive satellite schools, sharing a school's resources'
- 33% said 'Special needs school'
- 30% said 'Home school'
- 8% said 'Other'

Respondents were also asked to select which type of provision they thought would most suit their child's needs and which type of provision their child currently attended. The results are presented in table below. Most respondents said their child attended an 'other' type of provision or a large, inclusive school with LSA support (38%). However, only 9% and 16% respectively also said that they thought this type of provision most suited their child's needs. Although 27% of respondents said they thought a special Asperger needs school would best suit their child's needs, only 4% said their child currently attended this type of provision.

Table: Which type of educational provision would most suit your child's needs / does your child currently attend?

	Most suits needs	Child attends
	%	%
Home school	3%	4%
Home schooling with LEA supporting tutoring/resources	6%	3%
Flexible schooling	15%	1%
Large, inclusive school with LSA support	16%	38%
Special needs school	4%	8%
Special Asperger needs school	27%	4%
Special units attached to a school	16%	2%
Inclusive satellite schools, sharing a school's resources	4%	1%
Other	9%	38%
Total (Respondents)	320	315

Total (%)	100%	100%
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Educational Provision: Access to Education

Respondents were asked to select from a list anything that had been a barrier to obtaining a suitable education for their child. More than one response could be selected by each respondent. The results are presented in the table below. The most common barriers were the availability of appropriate schools locally (42%), the statementing process (32%) and obtaining a correct diagnosis (30%).

Table: Have any of the following things been a barrier to obtaining a suitable education for your child? (Multiple selection)

	n	%
Availability of appropriate schools locally	135	42%
Being statemented	101	32%
Obtaining a correct diagnosis	97	30%
Getting finance	63	20%
Availability of places in a school	44	14%
School exclusions	28	9%
Continuation of funding at chosen school	27	8%
Other	34	11%
None of these	45	14%
Total	320	N/A

Of 324 respondents, **35%** said their child had spent **significant amounts of time out of education** (n = 112). Of these:

- **33%** said their child had spent 1 to 3 months out of education
- **19%** said their child had spent 4 to 6 months out of education
- **10%** said their child had spent 7 to 11 months out of education
- **38%** said their child had spent 12 months or more out of education

Educational Provision: Satisfaction

A number of questions were asked to examine satisfaction in relation to aspects of educational provision. Firstly, respondents were asked directly to say how satisfied they were with the current educational provision of their child. Under a fifth said they were 'Very satisfied' and the same proportion of respondents said they were 'Very unsatisfied'. Just over a third said they were 'Satisfied' (39%).

Of 311 responding:

- **16%** said they were 'Very satisfied'
- **39%** said they were 'Satisfied'
- **30%** said they were 'Unsatisfied'
- **16%** said they were 'Very unsatisfied'

Respondents were also asked the extent to which they thought their child had received an adequate education or had reached their full potential. The results are presented in the table below. Under 10% said they thought their child had 'completely' received an adequate education or had reached their full potential, with only 2% saying they thought their child had 'completely' reached their full potential. **A quarter of the respondents (28%) said they did not think their child had received an adequate education** ('Not really' or 'Not at all'). **Half of the respondents (51%) said they did not think their child had reached their full potential** ('Not really' or 'Not at all').

Table: To what extent do you think your child has received an adequate education / has reached their full potential?

	Child received adequate education		Child has reached full potential	
	n	%	n	%
Completely	17	6%	7	2%
Mostly	89	29%	41	14%
To some extent	115	38%	101	33%
Not really	45	15%	84	28%
Not at all	39	13%	70	23%
Total	305	100%	303	100%

The lack of satisfaction with their children's experience of education is also evident in the level of future concerns described by respondents. The majority of respondents said they had concerns about future educational provision for their child. Of 299 responding, **260 (87%) said they had concerns about future education provision** and only 23 respondents said they had no concerns.

Educational Provision: Personal Concerns

In addition to the educational concerns expressed by a large proportion of the respondents, many respondents also expressed concerns for their child's emotional wellbeing in education. **Half of the respondents (53%) said they thought their child had not been happy throughout their education.** Only 18% said they thought their child had been happy ('Very happy' or 'Happy'), of whom only 4% said 'Very happy'.

Table: Overall, how happy has your child been throughout their education?

	n	%
Very happy	11	4%
Happy	41	14%
Just okay	89	29%
Unhappy	85	28%
Very unhappy	77	25%
Total	303	100%

Respondents also expressed concerns about other aspects of their children's emotional wellbeing at school. Most respondents said their children had experienced bullying at school, due to having Asperger's / Autism, with **only 7%** saying their child had **never experienced bullying** and with **42%** saying their child **experienced bullying 'often'**.

Of 296 responding:

- **42%** said their child had 'often' experienced bullying due to having Asperger's / Autism
- **27%** said their child had 'quite often' experienced bullying due to having Asperger's / Autism
- **24%** said their child had 'not often' experienced bullying due to having Asperger's / Autism
- **7%** said their child had 'not at all' experienced bullying due to having Asperger's / Autism

The 205 respondents who said their child had experienced bullying also described a poor view of the way their child's school had dealt with the bullying. **Only 4%** said the **school had dealt with the bullying 'Very well'** and **31%** said **'Not at all well'**, with a further **40%** saying **'Not very well'**.

Table: How well was the bullying dealt with at your child's school?

	n	%
Very well	8	4%
Quite well	51	25%
Not very well	82	40%
Not at all well	64	31%
Total	205	100%

Educational provision was also found to be failing to meet children's sensory needs, in the views of a large number of respondents. Of 203 respondents who said their child had sensory issues that might affect their ability to function in a school setting,⁴ **over half (60%) said their child's needs had not been met** ('not very well' or 'not at all well').

Of the 203 respondents:

- **10%** said their child's needs had been met 'very well'
- **30%** said their child's needs had been met 'quite well'
- **33%** said their child's needs had been met 'not very well'
- **27%** said their child's needs had been met 'not at all well'

⁴ This is 67% of 305 responding overall.

Mental and Emotional Wellbeing

Mental and Emotional Wellbeing: Concerns for Child

The majority of respondents described having concerns about their child's mental or emotional wellbeing, with 48% saying 'often' and 43% saying 'quite often' (of 301 responding). Only 9% said they had 'rarely' had concerns.

However, of the 267 responding who said they had concerns about their child's mental or emotional wellbeing, **only 10%** said they were **able to access as much help as they needed**. A third of the respondents said they were **not able to access help 'at all'** (30%).

Table: Were you able to access help for your child's mental or emotional needs?

	n	%
Yes, as much as I needed	27	10%
Some, but I needed more	160	60%
Not at all	80	30%
Total	267	100%

Mental and Emotional Wellbeing: Antipsychotic Drugs

Of 296 respondents, 52 said their child had been prescribed antipsychotic drugs (18%).⁵

Respondents were asked for how long their child took the drugs. Of 47 respondents:

- 8 said 'Under 1 month'
- 2 said '1 to 3 months'
- 1 said '4 to 6 months'
- 5 said '7 to 11 months'
- 6 said '1 to 2 years'
- 25 said 'Over 2 years'

Half of the respondents who said their child had been prescribed drugs said they thought their child was **on the drugs 'too long'** (22 of 41), with a third saying 'about right' (15 of 41) and a tenth saying 'not long enough' (4 of 41).

A third of the respondents said they thought **the effect of the drugs was 'not very beneficial' or 'not at all beneficial'** (14 of 46). However, two-thirds said 'quite beneficial' or 'very beneficial' (32 of 46, of whom 6 said 'very beneficial').

Similarly, **a third** of the respondents said they **thought their child was 'not really' or 'not at all' sufficiently monitored** while taking the drugs (16 of 48). However, two-thirds said they thought their child was 'definitely' or 'mostly' monitored sufficiently (32 of 48, of whom 9 said 'very beneficial').

⁵ Three respondents (1%) said they would 'rather not say'.

Mental and Emotional Wellbeing: Psychiatric Care

Of 298 respondents, 78 said their child had received psychiatric care (27%).⁶ Two-thirds of these respondents said they thought their child had received the right treatment and diagnosis (54 respondents said 'definitely' or 'mostly'). However, around a third said 'not really' or 'not at all'. Two-thirds of the respondents said their child had been able to access appropriate psychiatric care near to home (50 respondents), although 24 respondents said they had not been able to.

However, **half** of the respondents who said their child had received psychiatric care said they thought **the care their child received was 'poor' or 'very poor'** (39 respondents), with only 11 respondents describing the care as 'very good'.

Similarly, **nearly half** of the respondents said they thought psychiatric staff had **failed to demonstrate an understanding of Asperger's or Autism** (with 39 respondents saying 'not very well' or 'not at all well'). Only a quarter of respondents said that psychiatric staff had understood Asperger's or Autism 'Very well' (19 respondents). In addition, **nearly half** of the respondents said **the psychiatric environment had not been appropriate for their child** (with 35 saying 'inappropriate' or 'completely inappropriate').

Nevertheless, respondents were positive about the individual psychiatric care workers. **Three-quarters** of the respondents said the **staff had been kind and sympathetic** ('definitely' or 'mostly'), although 18 respondents said 'not really' or 'not at all'.

Mental and Emotional Wellbeing: Parental Concerns

Of 292 responding, the majority (**92%**) said that caring for a child with Asperger's syndrome or Autism also **had an impact on their own mental or emotional wellbeing**.⁷ Of these, **only 20%** said they were **able to access the help they needed** for their own mental or emotional needs, with **50%** saying 'not at all'.

Table: Have you been able to access the help you need for your own mental or emotional needs?

	n	%
Yes, as much as I need	51	20%
Some, but I need more	77	30%
Not at all	129	50%
Total	257	100%

⁶ 4 said they would 'rather not say' (1%).

⁷ 4 said they would 'rather not say' (1%).

Finances and Accommodation

Accommodation

Of the respondents answering the Support Services questionnaire, 51 said their child lived at home with them. Of these, **two-thirds** said they were **not satisfied with the support available** to their child, living at home with them (with 17 saying 'unsatisfied' and 19 saying 'very unsatisfied'). In addition, over half said they were not satisfied with the accommodation options available to their child (with 10 saying 'unsatisfied' and 17 saying 'very unsatisfied'). Only 4 respondents said they were 'very satisfied'.

Financial Help and Support

Of 271 responding, **96%** said they were **still financially supporting their child** (aged over 18).

Of the 273 respondents who said they could remember⁸, 68% said they had applied for the Disability Living Allowance (DLA). The most common reason given for not applying for the DLA was not knowing about it, given by a third of respondents (see table below).

Table: Please can you say why you have not applied for DLA on behalf of your child? Multiple Selection

	n	% (Respondents)
I did not know about DLA	31	30%
I did not know how to apply for DLA	12	12%
The forms were too difficult	11	11%
My child was not eligible for DLA	10	10%
I needed someone to help me	3	3%
Something else	38	37%
Total (Respondents)	104	N/A

The majority of respondents said they had found it difficult to fill in the DLA forms. Of 185 responding, **86%** said they had found it **'difficult' or 'very difficult' to fill in the DLA forms**, with only 2% saying 'very easy'.

Table: How easy or how difficult did you find it to fill in the DLA forms?

	n	%
Very easy	4	2%
Easy	23	12%
Difficult	75	41%
Very difficult	83	45%
Total	185	100%

⁸ 3 respondents said they could not remember.

In addition, **nearly two-thirds** of respondents said they had **not found the DLA questions useful or relevant** for assessing their child's current situation or needs (see table below). Of 181 responding, 52% said 'not very useful / relevant' and 13% said 'not at all useful / relevant', with only 2% saying 'very useful / relevant'.

Table: How useful or relevant did you find the DLA questions for assessing your child's current situation or needs?

	n	%
Very useful/relevant	4	2%
Useful/relevant	59	33%
Not very useful/relevant	94	52%
Not at all useful/relevant	24	13%
Total	181	100%

Of the 191 respondents who said they had an opinion⁹, most said they thought the Disability Living Allowance should be paid directly into a young person's bank account from the age of 18, with:

- **18%** saying from the age of 16
- **4%** saying from the age of 17
- **54%** saying from the age of 18
- **25%** saying from other ages

⁹ 76 respondents said they did not know or had no opinion.