

**Real-world experiences in autistic adult diagnostic services and post-diagnostic support  
and alignment with services guidelines: Results from the ASDEU study.**

Author Note

We have no conflict of interest to disclose.

Supplementary Material 1

Survey’s questions and answer choices for autistic adults, carers, cared-for adults and professionals

Question autistic adult	Question carer	Question professional	Answer autistic adult	Answer carer	Answer professional
Background information					
N/A	N/A	Thinking of your work history, what job or career title fits you best?	N/A	N/A	General practitioner
					Psychiatrist
					Medical specialist, other than psychiatrist
					Nurse
					Other medical professional
					Psychologist
					Social worker
					Teacher/pedagogue
					Teaching assistant/nursery assistant
					Mental health therapist
					Physical or occupational therapist

I work in the area of criminal justice (e.g., police, courts, legal advocate)  
Other, please specify

N/A

N/A

Thinking of your work history, how many years in total have you been in jobs in adult services and care (social, medical, or other services)

N/A

N/A

< 1 year

1-2 years

3-5 years

6-10 years

> 10 years

What is your gender?

What is your gender?

What is your gender?

Male

Male

Male

Female

Female

Female

Other/no answer

Other/no answer

Other/no answer

How old are you?

How old are you?

N/A

18-25

18-25

N/A

26-35

26-35

36-45

36-45

46-55

46-55

56-64

56-64

			> 65	> 65	
N/A	How many years of education did you complete?	N/A	N/A	< 10 years	N/A
				10-12 years	
				13-16 years	
				> 16 years	
Are you going to a school, a home school or in an education program now?	N/A	N/A	Yes, full time	N/A	N/A
			Yes, part time		
			No		
If no, do you remember your age when you finished your education?	N/A	N/A	Yes	N/A	N/A
			No		
How old were you when you finished your education?	N/A	N/A		N/A	N/A
If yes, what kind of education are you in now?	N/A	N/A	Primary level school	N/A	N/A
			Secondary level school (for example high school or gymnasium)		
			Technical, vocational or job training school		
			College or university		

What kind of education were you in when you finished your education:	N/A	N/A	Secondary - level school (for example high school or gymnasium) Technical, vocational or job training school College or university  Don't know	N/A	N/A
Are you:	What is your current employment status now? Pick the answer that fits you best.	N/A	Secondary - level school (for example high school or gymnasium) N/A	Student (carer)  Unemployed  Employed (part time or full time) Self-employed (carer)  Retired (carer)  Volunteer	N/A
If you are unemployed, is it because:	N/A	N/A	You are a student  You are retired  You are looking for a job  You believe that you cannot find a job	N/A	N/A

You have a disability that prevents you from having a job  
Other, please specify

What country do you live in?

What country do you live in?

What country do you work in?

Austria

Austria

Austria

Belgium

Belgium

Belgium

Bulgaria

Bulgaria

Bulgaria

Denmark

Denmark

Denmark

England

England

England

Finland

Finland

Finland

France

France

France

Iceland

Iceland

Iceland

Italy

Italy

Italy

Northern Ireland

Northern Ireland

Northern Ireland

Poland

Poland

Poland

Portugal

Portugal

Portugal

Republic of Ireland

Republic of Ireland

Republic of Ireland

			Romania	Romania	Romania
			Scotland	Scotland	Scotland
			Spain	Spain	Spain
			Wales	Wales	Wales
			Other, specify	Other, specify	Other, specify
N/A	What is the autistic adult's gender?	N/A	N/A	Male	N/A
				Female	
				Other/no answer	
N/A	How old is the autistic adult?	N/A	N/A	18-25	N/A
				26-35	
				36-45	
				46-55	
				56-64	
				> 65	
N/A	How many years have you known the	N/A	N/A	Less than 1 year	N/A

	autistic adult?			1-5 years	
				5-10 years	
				More than 10 years but not the adult's whole life	
				The adult's whole life	
N/A	How are you related to the autistic adult?	N/A	N/A	Parent	N/A
				Other family member related by blood (not a parent, but for example a child, cousin, grand parent, uncle etc.)	
				Spouse or partner	
				A carer, but not a family member, spouse or partner	
Where do you live now?	Where is the autistic adult living now?	Thinking of your current job location where is it located?	Capital city	Capital city	Capital city
			Other than a capital city	Other than a capital city	Other than a capital city
How many people live in the community where you live now? (Answer the best you can)	How many people live in the community where the autistic adult lives now? Answer as best you can	How many people live in the community where your current job is located?	< 1.000 people	< 1.000 people	< 1.000 people
			1.000-20.000 people	1.000-20.000 people	1.000-20.000 people
			20.000-100.000 people	20.000-100.000 people	20.000-100.000 people
			100.000-1.000.000	100.000-1.000.000	100.000-1.000.000
			> 1.000.000	> 1.000.000	> 1.000.000



			Don't Know	Don't Know	Don't Know
N/A	Pick the description that best fits the autistic adult.	N/A	N/A	Has a high level of independence Has some independence but needs support Needs a high level of support in daily living Needs high level institution-like care	N/A
N/A	N/A	The experience and knowledge about services for adults that you have from your current job is:	N/A	N/A	Most closely connected to your current job location (e.g., capital city or small town) Most closely connected to your current job location and a wider area (e.g., the region or state where your job is located) Most closely connected to the whole country
Autism spectrum diagnosis and support after the diagnosis, in adulthood					
N/A	N/A	Do you have knowledge of and current work experience (in the last 2 years) in diagnostic procedures in adults and post-diagnosis support for autistic adults?	N/A	N/A	Yes No
Were you 18 years of age or older when you got the autism spectrum diagnosis?	Did the adult get the autism spectrum diagnosis when he or she was 18 years of age or older?	N/A	Yes  I don't have a formal diagnosis for autism spectrum	Yes  No, he/she was less than 18 years old at the time of the autism spectrum diagnosis	N/A

			Don't know	He/she does not have a formal autism spectrum diagnosis Don't know	
If yes, do you remember your age when you got the autism spectrum diagnosis?	If yes, do you remember the adult's age when he/she got the autism spectrum diagnosis?	N/A	Yes, I remember my age	Yes, I remember his/her age	N/A
			No, I don't remember my exact age at the time, but I was older than 18	No, I don't remember his/her age at the time, but he/she was older than 18	
How old were you when you got the autism spectrum diagnosis?	How old was the adult when he/she got the autism spectrum diagnosis?	N/A			N/A
N/A	You should answer this section ONLY if you have knowledge and experience with the adult's autism spectrum diagnostic process	N/A	N/A	Yes, I have knowledge and experience with the adult's diagnostic process No, I do not have knowledge and experience with the adult's diagnostic process	N/A
Based on your experience and knowledge, information on how to get a diagnostic evaluation for autism spectrum in adulthood in your country, is:	Based on your experience and knowledge, information on how to get a diagnostic evaluation for autism spectrum in adulthood is:	Based on your current work experience and knowledge, information on how to get a diagnostic evaluation for autism spectrum is:	Available on the internet (Yes; No; Don't know) Available in print (Yes; No; Don't know) Easy to find (Yes; No; Don't know) Easy to understand (Yes; No; Don't know)	Available on the internet (Yes; No; Don't know) Available in print (Yes; No; Don't know) Easy to find (Yes; No; Don't know) Easy to understand (Yes; No; Don't know)	Available on the internet (Yes; No; Don't know) Available in print (Yes; No; Don't know) Easy to locate (Yes; No; Don't know) Easy to understand (Yes; No; Don't know)
What was the waiting time between the request for a diagnostic evaluation	What was the waiting time between the request for a diagnostic	Thinking of the adult diagnostic service for autism spectrum that you know best, what is the	< 1 month 1-3 months	< 1 month 1-3 months	< 1 month 1-3 months

and the beginning of the evaluation for you?	evaluation and the beginning of the evaluation for the adult?	waiting time between the referral (or the request for an evaluation) and the beginning of the evaluation?	3-6 months  > 6 months  Don't know	3-6 months  > 6 months  Don't know	3-6 months  > 6 months  Don't know
Based on your experience, were the following factors part of your diagnostic evaluation for autism spectrum?	Were the following factors part of the adult's diagnostic evaluation for autism spectrum?	Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors parts of the diagnostic evaluation for autism spectrum in adults?	A multidisciplinary team (a team of different kinds of experts) carried out the evaluation (Yes; No; Don't know)  N/A   A family member, carer, partner, or other knowledgeable person was asked about your symptoms (Yes; No; Don't know)  N/A	A multidisciplinary team (a team of different kinds of experts) carried out the evaluation (Yes; No; Don't know)  N/A   You or some other knowledgeable person was asked about the adult's symptoms (Yes; No; Don't know)  N/A	Multidisciplinary teams carry out the evaluation (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Consultation takes place with other experts, as needed (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Consultation takes place with a family member, carer, partner, or another knowledgeable person (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Evaluation of core autism spectrum behaviors (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Direct observation in social settings (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)

		Use of standard tests for autism spectrum (e.g., ADOS) (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Use of standard tests for cognitive or psychological functioning (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Physical examination (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Biological tests (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked to fill out a questionnaire about your symptoms (Yes; No; Don't know)	N/A	N/A
You had a blood test for genetic studies (Yes; No; Don't know)	The adult had a genetic test (Yes; No; Don't know)	Genetic tests (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You had a scan, for example a brain scan (Yes; No; Don't know)	The adult had a brain scan (Yes; No; Don't know)	Neuroimaging (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
N/A	The adult's development was looked into, for example when the adult first made	Evaluation of history of neurodevelopmental disorders (Standard routine practice; Not

	words (Yes; No; Don't know)	standard practice, but often considered; Rarely considered; Never considered; Don't know)
N/A	They looked into whether the adult had behavior problems (Yes; No; Don't know)	Evaluation of behavioral problems (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked about how well you did in different settings (home, school, job) (Yes; No; Don't know)	They looked into how well the adult did in different settings (home, school, job) (Yes; No; Don't know)	Evaluation of functioning in different settings (home, school, job) (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked if you had physical problems or mental problems (Yes; No; Don't know)	They looked into whether the adult had physical or mental disorders (Yes; No; Don't know)	Evaluation of history of physical or other mental comorbid disorders (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked if you had development problems, like ADHD or learning problems (Yes; No; Don't know)	They looked into whether the adult had development problems, like ADHD or learning problems (Yes; No; Don't know)	Evaluation of early developmental history (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked if you had difficulties with language or the way you communicate with others (Yes; No; Don't know)	They looked into whether the adult had language or communication problems (Yes; No; Don't know)	Evaluation of language or communication problems (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
You were asked if you had sensory problems, like being sensitive to noise or bright lights (Yes; No; Don't know)	They looked into whether the adult had sensory problems, like being sensitive to noise or bright lights (Yes; No; Don't know)	Evaluation of sensory problems (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)

			You were asked if you sometimes hurt yourself or hurt others (Yes; No; Don't know)	They looked into whether the adult hurt him/herself or hurt others (Yes; No; Don't know)	Evaluation of behavior related to self-harm or harm to others (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
			You were asked if you had ever been abused, neglected or been taken advantage of (Yes; No; Don't know)	They looked into whether the adult had ever been abused, neglected or been taken advantage of (Yes; No; Don't know)	Evaluation of experience of abuse, neglect or exploitation (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
			You were asked if you ever had contact with the police (Yes; No; Don't know)	They looked into whether the adult ever had contact with the police (Yes; No; Don't know)	Evaluation of police encounters (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
After you got the autism spectrum diagnosis, which of the following things happened?	After the adult got the autism spectrum diagnosis, which of the following things happened?	Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors considered as parts of the post-diagnostic activities for autistic adults?	Got written recommendations for care and follow-up for non-medical problems (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know) N/A	The adult got written recommendations for his/her care and follow-up for non-medical problems (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know) The adult got written recommendations for managing risks (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know)	Written recommendations for care and follow-up for non-medical issues, when needed (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Written recommendations for managing risks, when needed (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
			Got written recommendations for health care (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know) N/A	The adult got written recommendations for health care (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know) The adult got written recommendations for how to manage a crisis (Yes, and it	Written recommendations for health care guidance, when needed (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know) Written recommendations for crisis management, when needed (Standard routine practice; Not

			Got a 'health passport' to carry that has important information about your needs and care (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know)	was needed; No, but it was needed; No, and it was NOT needed; Don't know) The adult got a 'health passport' to carry that has important information about his/her needs and care (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know)	standard practice, but often considered; Rarely considered; Never considered; Don't know) A 'health passport' for the adults to carry with them that has important information about the person's needs and care (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
			Got a referral for specialist care for health or medical problems (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know)	The adult got a referral for specialist care for health or medical problems (Yes, and it was needed; No, but it was needed; No, and it was NOT needed; Don't know)	Referral for specialist care for health or medical conditions, when needed (Standard routine practice; Not standard practice, but often considered; Rarely considered; Never considered; Don't know)
Based on your experience and knowledge, how many diagnosis services in your country are specific for autism spectrum in adults?	Based on your experience and knowledge, how many diagnosis services in your country are specific for autism spectrum in adults?	Based on your current work experience and knowledge, how many diagnostic services in your country are specific for autism spectrum in adults?	0	0	0
			1-5	1-5	1-5
			6-10	6-10	6-10
			> 10	> 10	> 10
Do you know of a diagnostic service for adults, in your area or elsewhere in your	Do you know of a diagnostic service for adults, in your area or elsewhere in	Do you know of a diagnostic service for adults, in the "area where you work now" or	There are some, but I don't know how many in my country I don't know if there are any that are specific for autism spectrum in my country Yes	There are some, but I don't know how many in my country I don't know if there are any that are specific for autism spectrum in my country Yes	There are some, but I don't know how many in my country I don't know if there are any that are specific for autism spectrum in my country Yes
			No	No	No

country, which works very well for adults on the autism spectrum?	your country, which works very well for autistic adults?	elsewhere in your country, which has a reputation of exceptional service for diagnosing autism spectrum?	Don't know	Don't know	Don't know
If yes, what is it called? Fill in blank (if you know more than 1, name your first choice)	If yes, what is it called? Fill in blank (if you know more than 1, name your first choice)	If yes, what is it called? Fill in blank (if you know more than 1, name your first choice)	_____	_____	_____
If yes, where is it located? Fill in blank (if you know more than 1, name your first choice)	If yes, where is it located? Fill in blank (if you know more than 1, name your first choice)	If yes, where is it located? Fill in blank (if you know more than 1, name your first choice)	_____	_____	_____

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## Supplementary Material 2

### *Demographic characteristics of autistic adults, carers, cared-for adults and professionals*

Characteristic	Answer	Autistic adult ( <i>N</i> =356)	Carer / Cared-for adult ( <i>N</i> =88)	Professional ( <i>N</i> =151)
Gender	Female	259 (72.8)	79 (89.8) / 34 (38.6)	112 (74.2)
	Male	86 (24.2)	9 (10.2) / 54 (61.4)	36 (23.8)
	Other or no answer	11 (3.9)	0 / 0	3 (2.0)
Age (years)	18-25	40 (11.2)	0/ 21 (23.8)	N/A
	26-35	120 (33.7)	10 (11.4) / 36 (40.9)	
	36-45	100 (28.1)	9 (10.2) / 15 (17.1)	
	46-55	77 (21.6)	24 (27.3) / 15 (17.1)	
	56-64	18 (5.1)	28 (31.8) / 1 (1.1)	
	> 65	1 (0.3)	17 (19.3) / 0	
Living area				
Country	Denmark	157 (44.1)	37 (42.1)	24 (15.9)

	Finland	49 (13.8)	5 (5.7)	42 (27.8)
	France	48 (13.5)	19 (21.6)	28 (18.5)
	Spain	17 (4.8)	10 (11.4)	15 (9.9)
	Italy	12 (3.4)	4 (4.6)	20 (13.2)
	Poland	23 (6.5)	3 (3.4)	8 (5.3)
	Iceland	15 (4.2)	5 (5.7)	6 (4.0)
	United Kingdom	21 (5.9)	0	3 (1.9)
	Republic of Ireland	9 (2.5)	5 (5.7)	0
	Germany	5 (1.4)	0	3 (1.9)
	Portugal	0	0	2 (1.3)
Living area	Capital city	94 (26.4)	30 (34.1)	52 (34.4)
	Other than a capital city	262 (73.6)	58 (65.9)	99 (65.6)
Community size	< 1.000 people	24 (6.7)	7 (8.0)	2 (1.3)
	1.000-20.000 people	67 (18.8)	21 (23.9)	16 (10.6)
	20.000-100.000 people	93 (26.1)	29 (33.0)	46 (30.5)

	100.000-1.000.000	105 (29.5)	16 (18.2)	60 (39.7)
	> 1.000.000	37 (10.4)	9 (10.2)	27 (17.9)
	Don't Know	30 (8.4)	6 (6.8)	0
Education				
Adult is attending school, home school or education program at the time of survey completion	Yes, full time	33 (9.3)	N/A	N/A
	Yes, part time	34 (9.5)		
	No	289 (81.2)		
If yes, actual education level	Primary level school	1 (1.5)	N/A	N/A
	Secondary level school	6 (9.0)		
	Technical, vocational or job training school	7 (10.4)		
	College or University	53 (79.1)		
If no, completed education level	Primary level school	23 (8.0)	N/A	N/A
	Secondary level school	49 (17.0)		
	Technical, vocational or job training school	72 (24.9)		
	College or University	137 (47.4)		

	Don't Know	8 (2.8)		
Adult remember the age when completing education	Yes	262 (90.7)	N/A	N/A
	No	27 (9.3)		
Adult age at completed education	Mean $\pm$ Standard Deviation [Range]	29.3 $\pm$ 96.7 [6-52]	N/A	N/A
Carer years of education	< 10 years	N/A	11 (12.5)	N/A
	10-12 years		8 (9.1)	
	13-16 years		23 (26.1)	
	>16 years		39 (44.3)	
	Other		7 (8.0)	
Employment				
Current employment status	Unemployed	182 (51.1)	10 (11.4)	N/A
	Employed (part time o full time)	124 (34.8)	47 (53.4)	
	Self-employed	21 (5.9)	3 (3.4)	
	Student	N/A	2 (2.3)	

If unemployed, reasons for unemployment	Volunteer	29 (8.2)	2 (2.3)	
	Retired	N/A	24 (27.3)	
	A disability that prevents from having a job	65 (35.7)	N/A	N/A
	Student	18 (9.9)		
	Looking for a job	24 (13.2)		
	Believing that she/he cannot find a job	12 (6.6)		
	Retired	19 (10.4)		
	Other	44 (24.2)		
Adult's ability to complete the survey with little or no help (N=297)				
The survey was filled in by autistic adults with little or no help	Alone	289 (97.3)	N/A	N/A
	With a parent	4 (1.6)		
	With a spouse or partner	2 (0.7)		
	With a professional	0		
	Other	2 (0.7)		
Carer' relationship with the adult				

Years of knowledge of the adult	<1 year	N/A	1 (1.1)	N/A
	1-5 years		3 (3.4)	
	5-10 years		4 (4.6)	
	>10 years but not the adult's whole life		15 (17.1)	
	The adult's whole life		65 (73.9)	
Relationship with the adult	Parent	N/A	60 (68.2)	N/A
	Other family member related by blood		9 (10.2)	
	Spouse or partner		16 (18.2)	
	A carer, but not a family member, spouse or partner		3 (3.4)	
Level of independence of the autistic adult	High level of independence	N/A	13 (14.8)	N/A
	Some independence but needs support		48 (54.6)	
	Needs a high level of support in daily living		24 (27.6)	
	Needs high level institution-like care		3 (3.4)	
Professionals' backgrounds and characteristics of their workplace				
Professional type	Psychologist	N/A	N/A	67 (44.4)

	Other			18 (11.9)
	Psychiatrist			18 (11.9)
	Teacher/pedagogue			16 (10.6)
	Nurse			7 (4.6)
	General practitioner			7 (4.6)
	Medical specialist, other than psychiatrist			6 (4.0)
	Social worker			4 (2.7)
	Physical or occupational therapist			4 (2.7)
	Teaching assistant/nursery assistant			3 (1.9)
	Other medical professional (open answer)			1 (0.7)
	Mental health therapist			1 (0.7)
	Criminal justice (e.g. police, courts, legal advocate)			0
Years in jobs in adult services and care	<1 year	N/A	N/A	6 (4.0)
	1-2 years			11 (7.3)
	3-5 years			17 (11.3)

Source of experience and knowledge about services for adults	6-10 years			40 (26.5)
	>10 years			77 (51.0)
	Current job location (e.g., capital city or small town)	N/A	N/A	48 (31.8)
	Current job location and a wider area (e.g., the region or state where your job is located)			79 (52.3)
	Most closely connected to the whole country			24 (15.9)

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*Note.* N/A=Question was not presented to the respondent group. Values expressed as number of responders and frequencies (in parenthesis).



### Supplementary material 3

*Stratified results of age at diagnosis in adulthood, waiting time for service and knowledge of local diagnostic services by autistic by adults' gender, high/some independence and high level of support/institution-like care of the autistic adult cared reported by carers*

Question	Answer	Autistic adult			Carer		
		Female	Male	Total	High or some independence	High-level of support or institution-like care	Total
		<i>n (%)</i>	<i>n (%)</i>	<i>N (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>N (%)</i>
Diagnosis in adulthood	Yes	259 (75.1)	86 (24.1)	345 (100.0)	61 (69.3)	27 (30.7)	88 (100.0)
Remember the age when the adult got the autism spectrum diagnosis	Yes	255 (98.5)	85 (98.8)	340 (98.6)	60 (98.4)	22 (81.5)	82 (93.2)
	No	4 (1.5)	1 (1.2)	5 (1.4)	1 (1.6)	5 (18.5)	6 (6.8)
Waiting time between the request for a diagnostic evaluation and the beginning of the evaluation	< 1 month	34 (13.1)	11 (13.1)	45 (13.1)	5 (10.4)	0 (0.0)	5 (7.4)
	1-3 months	81 (31.3)	23 (27.4)	104 (30.3)	16 (33.3)	2 (10.0)	18 (26.5)
	3-6 months	47 (18.2)	19 (22.6)	66 (19.2)	8 (16.7)	5 (25.0)	13 (19.1)
	> 6 months	62 (23.9)	23 (27.4)	85 (24.78)	15 (31.3)	10 50.0)	25 (36.8)
	Don't know	35 (13.5)	8 (9.5)	43 (12.5)	4 (8.3)	3 (15.0)	7 (10.3)
Number of diagnosis services known in the country specific for	0	16 (4.5)	6 (3.8)	22 (4.3)	10 (4.1)	11 (4.5)	21 (4.3)
	1-5	67 (18.7)	30 (18.9)	97 (18.7)	55 (22.3)	40 (16.2)	95 (19.2)

autistic adults	6-10	10 (2.8)	3 (1.9)	13 (2.5)	12 (4.9)	9 (3.6)	21 (4.3)
	> 10	20 (5.6)	14 (8.8)	34 (6.6)	22 (8.9)	51 (20.7)	73 (14.8)
	Don't know how many in my country	176 (49.0)	82 (51.6)	258 (49.8)	99 (40.1)	106 (42.9)	205 (41.5)
	Don't know if there are any specific for autism spectrum in the country	70 (19.5)	24 (15.1)	94 (18.2)	49 (19.8)	30 (12.1)	79 (16.0)
Knowledge of good local models of autism diagnosis service	Yes	92 (25.8)	54 (34.0)	146 (28.3)	80 (32.7)	63 (25.6)	143 (29.1)
	No	169 (47.3)	59 (37.1)	142 (27.5)	106 (43.3)	91 (37.0)	197 (40.1)
	Don't know	96 (26.9)	46 (28.9)	142 (27.5)	59 (24.1)	92 (37.4)	151 (30.8)

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## Supplementary material 4

### *Knowledge of a good local model of autism diagnosis service by countries*

	Autstic adult (N=535)					Carer (N=491)					Professional (N=138)			
Answer	Yes	No	Do not know	Total		Yes	No	Do not know	Total		Yes	No	Do not know	Total
	<i>n (%)</i>			<i>N</i>		<i>n (%)</i>			<i>N</i>		<i>n (%)</i>			<i>N</i>
Knowledge of a good local model of autism diagnosis service														
Denmark	28 (13.0)	116 (53.7)	72 (33.3)	216		25 (17.5)	64 (44.8)	54 (37.8)	143		8 (38.1)	6 (28.6)	7 (33.3)	21
Finland	22 (32.3)	24 (35.9)	22 (32.2)	68		11 (28.2)	9 (23.1)	19 (48.7)	39		15 (39.5)	6 (15.8)	17 (44.7)	38
France	33 (46.5)	31 (43.7)	7 (9.9)	71		33 (45.8)	28 (38.9)	11 (15.3)	72		23 (85.2)	2 (7.4)	2 (7.4)	27
Spain	9 (36.0)	9 (36.0)	7 (28.0)	25		44 (47.3)	32 (34.4)	17 (18.3)	93		8 (61.5)	4 (30.8)	1 (7.7)	13
Italy	17 (37.0)	16 (34.8)	13 (28.3)	46		9 (26.5)	17 (50.0)	8 (23.5)	34		15 (79.0)	3 (15.8)	1 (5.3)	19
Poland	22 (47.8)	16 (34.8)	8 (17.4)	46		22 (40.0)	23 (41.8)	10 (18.2)	55		6 (75.0)	0	2 (25.0)	8
Iceland	4 (20.0)	8 (40.0)	8 (40.0)	20		6 (13.3)	18 (40.0)	21 (46.7)	45		3 (75.0)	1 (25.0)	0	4

United Kingdom	11 (47.8)	6 (26.1)	6 (26.1)	23	0	0	0	0	4 (66.7)	0	2 (33.3)	6
Republic of Ireland	2 (14.3)	8 (57.1)	4 (28.6)	14	1 (10.0)	6 (60.0)	3 (30.0)	10	0	0	0	0
German	5 (83.3)	1 (16.7)	0	6	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	2 (100.0)	0	0	2

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## Supplementary Material 5

*Stratified results of information on how to get a diagnostic evaluation for autism in adulthood by autistic by adults' gender, high/some independence and high level of support/institution-like care of the autistic adult cared reported by carers*

Answer	Autistic adult (N = 343)						Carer (N = 68)					
	Yes		No		Do not know		Yes		No		Do not know	
	Female	Male	Female	Male	Female	Male	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care
Available on internet	180 (69.5)	59 (70.2)	37 (14.3)	11 (13.1)	42 (16.2)	14 (16.7)	30 (62.5)	10 (50.0)	5 (10.4)	5 (25.0)	13 (27.1)	5 (25.0)
Available in print	74 (28.6)	33 (39.3)	83 (32.1)	19 (22.6)	102 (39.4)	32 (38.1)	20 (41.7)	8 (40.0)	9 (18.8)	6 (30.0)	19 (39.6)	6 (30.0)
Easy to find	69 (26.6)	31 (36.9)	154 (59.5)	44 (52.4)	36 (13.9)	9 (10.7)	10 (20.8)	3 (15.0)	29 (60.4)	12 (60.0)	9 (18.8)	5 (25.0)
Easy to understand	73 (28.2)	36 (42.9)	135 (52.1)	37 (44.1)	51 (19.7)	11 (13.1)	16 (33.3)	5 (25.0)	22 (45.8)	8 (40.0)	10 (20.8)	7 (35.0)

*Note.* Values expressed as number of responders and frequencies (in parenthesis). The original survey question was the following among all groups: *Based on your experience and knowledge, information on how to get a diagnostic evaluation for autism spectrum in adulthood is: .....*

## Supplementary material 6

*Is information on how to get a diagnostic evaluation easy to find or understand for autism in adulthood? Analysis by countries*

Answer	Autstic adult (N=354)				Carer (N=68)				Professional (N=150)			
	Yes	No	Do not know	Total	Yes	No	Do not know	Total	Yes	No	Do not know	Total
	<i>n (%)</i>			<i>N</i>	<i>n (%)</i>			<i>N</i>	<i>n (%)</i>			<i>N</i>
Easy to find												
Denmark	49 (31.4)	81 (51.9)	26 (16.7)	156	7 (20.6)	21 (61.8)	6 (17.6)	34	10 (43.5)	6 (26.1)	7 (30.4)	23
Finland	12 (24.5)	34 (69.4)	3 (6.1)	49	1 (25.0)	2 (50.0)	1 (25.0)	4	19 (45.2)	15 (35.7)	8 (19.1)	42
France	13 (27.1)	31 (64.6)	4 (8.3)	48	2 (15.4)	9 (69.2)	2 (15.4)	13	10 (35.7)	10 (35.7)	8 (28.6)	28
Spain	6 (35.3)	9 (52.9)	2 (11.8)	17	1 (25.0)	1 (25.0)	2 (50.0)	4	6 (40.0)	7 (46.7)	2 (13.3)	15
Italy	4 (33.3)	7 (58.3)	1 (8.3)	12	1 (25.0)	1 (25.0)	2 (50.0)	4	10 (50.0)	8 (40.0)	2 (10.0)	20
Poland	7 (31.8)	13 (59.1)	2 (9.1)	22	0	1 (100.0)	0	1	2 (25.0)	4 (50.0)	2 (25.0)	8
Iceland	1 (6.7)	11 (73.3)	3 (20.0)	15	0	3 (100.0)	0	3	3 (50.0)	2 (33.3)	1 (16.7)	6

United Kingdom	7 (33.3)	12 (57.1)	9 (9.5)	21	0	0	0	0	5 (83.3)	1 (16.7)	0	6
Republic of Ireland	3 (33.3)	4 (44.4)	2 (22.2)	9	1 (20.0)	3 (60.0)	1 (20.0)	5	0	0	0	0
German	1 (20.0)	4 (80.0)	0	5	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	0	1 (50.0)	2

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#### Easy to understand

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Denmark	47 (30.1)	75 (48.1)	34 (21.8)	156	7 (20.6)	16 (47.1)	11 (32.3)	34	8 (34.8)	8 (34.8)	7 (30.4)	23
Finland	15 (30.6)	25 (51.0)	9 (18.4)	49	1 (25.0)	2 (50.0)	1 (25.0)	4	19 (45.2)	12 (28.6)	11 (26.2)	42
France	19 (39.6)	25 (52.1)	4 (8.3)	48	6 (46.1)	5 (38.5)	2 (15.4)	13	11 (39.3)	10 (35.7)	7 (25.0)	28
Spain	6 (35.3)	10 (58.8)	1 (5.9)	17	1 (25.0)	2 (50.0)	1 (25.0)	4	6 (40.0)	8 (53.3)	1 (6.7)	15
Italy	5 (41.7)	5 (41.7)	2 (16.7)	12	2 (50.0)	1 (25.0)	1 (25.0)	4	9 (45.0)	9 (45.0)	2 (10.0)	20
Poland	11 (50.0)	8 (36.4)	3 (13.6)	22	1 (100.0)	0	0	1	6 (75.0)	1 (12.5)	1 (12.5)	8
Iceland	1 (6.7)	11	3 (20.0)	15	1 (33.3)	2 (66.7)	0	3				

		(73.3)								4 (66.7)	1 (16.7)	1 (16.7)	6
United Kingdom	6 (28.6)	12 (57.1)	3 (14.3)	21	0	0	0	0		4 (66.7)	1 (16.7)	1 (16.7)	6
Republic of Ireland	3 (33.3)	3 (33.3)	3 (33.3)	9	2 (40.0)	2 (40.0)	1 (20.0)	5		0	0	0	0
German	1 (20.0)	4 (80.0)	0	5	0	0	0	0		0	0	0	0
Portugal	0	0	0	0	0	0	0	0		1 (50.0)	0	1 (50.0)	2

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*Note.* The survey question was the following among all groups: *Based on your experience and knowledge, information on how to get a diagnostic evaluation for autism spectrum in adulthood is: ...*



## Supplementary material 7

*Number of recommended features for an adult diagnostic evaluation for autism spectrum reported by responders*

Number of recommendations	Autistic adult (N=347)	Carer (N=64)	Professional (N=144)
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
0	3 (0.9)	1 (1.6)	5 (3.5)
1	6 (1.7)	0 (0.0)	0 (0.0)
2	7 (2.0)	2 (3.1)	2 (1.4)
3	12 (3.5)	1 (0.0)	1 (0.7)
4	20 (5.8)	1 (1.6)	0 (0.0)
5	36 (10.4)	2 (3.1)	1 (0.7)
6	38 (10.9)	2 (3.1)	1 (0.7)
7	54 (15.6)	5 (7.8)	0 (0.0)
8	63 (18.2)	7 (10.9)	1 (0.7)
9	54 (15.6)	12 (18.8)	2 (1.4)
10	31 (8.9)	21 (32.8)	3 (2.1)

11	23 (6.6)	6 (9.4)	8 (5.6)
12		4 (6.3)	8 (5.6)
13			9 (6.3)
14			9 (6.3)
15			13 (9.0)
16			25 (17.4)
17			22 (15.3)
18			34 (23.6)

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## Supplementary material 8

*Stratified results of information on recommended and NOT recommended features for an adult diagnostic evaluation for autism spectrum by autistic by adults' gender, high/some independence and high level of support/institution-like care of the autistic adult cared reported by carers*

Answer	Autistic adult ( <i>N</i> = 337)						Carer ( <i>N</i> = 64)					
	Recommended features											
	Female	Male	Female	Male	Female	Male	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care
	Yes		No		Do not know		Yes		No		Do not know	
Multidisciplina ry team	116 (45.1)	33 (41.3)	117 (45.5)	46 (57.5)	24 (9.3)	1 (1.3)	23 (51.1)	12 (63.2)	21 (46.7)	7 (36.8)	1 (2.2)	0 (0.0)
Close person asked about adult’s symptoms	169 (65.8)	54 (67.5)	82 (31.9)	26 (32.5)	6 (2.3)	0 (0.0)	37 (82.2)	14 (73.7)	8 (17.8)	5 (26.3)	0 (0.0)	0 (0.0)
Questionnaire on symptoms	192 (74.7)	48 (60.0)	58 (22.6)	29 (36.3)	7 (2.7)	3 (3.8)			N/A			

Function evaluated in different settings	230 (89.5)	73 (91.3)	20 (7.8)	4 (5.0)	7 (2.7)	3 (3.8)		40 (88.9)	16 (84.2)	4 (8.9)	3 (15.8)	1 (2.2)	0 (0.0)
Physical or mental problems	217 (84.4)	67 (83.7)	26 (10.1)	8 (10.0)	14 (5.5)	5 (6.3)		40 (88.9)	14 (73.7)	4 (8.9)	3 (15.8)	1 (2.2)	2 (10.5)
Development problems like ADHD	200 (77.8)	55 (68.8)	40 (15.6)	15 (18.8)	17 (6.6)	10 (12.5)		40 (88.9)	15 (79.0)	5 (11.1)	4 (21.1)	0 (0.0)	0 (0.0)
Language / communication difficulties	223 (86.8)	67 (83.8)	24 (9.3)	8 (10.0)	10 (3.9)	5 (6.3)		41 (91.1)	19 (100.0)	4 (8.9)	0 (0.0)	0 (0.0)	0 (0.0)
Sensory problems	216 (84.1)	61 (76.3)	31 (12.1)	13 (16.3)	10 (3.9)	6 (7.5)		35 (77.8)	11 (57.9)	4 (8.9)	8 (42.1)	6 (13.3)	0 (0.0)
Self-harm or harm to others	147 (57.2)	42 (52.5)	81 (31.5)	24 (30.0)	29 (11.3)	14 (17.5)		33 (73.3)	15 (79.0)	8 (17.8)	4 (21.1)	4 (8.9)	0 (0.0)
Being abused / neglected or taken advantage of	110 (42.8)	29 (36.3)	115 (44.8)	38 (47.5)	32 (12.5)	13 (16.3)		19 (42.2)	8 (42.1)	16 (35.6)	9 (47.4)	10 (22.2)	2 (10.5)
Contact with the police	43 (16.7)	21 (26.3)	178 (69.3)	53 (66.3)	36 (14.0)	6 (7.5)		5 (11.1)	3 (15.8)	26 (57.8)	15 (79.0)	14 (31.1)	1 (5.3)
Adult's development			N/A					39 (86.7)	13 (68.4)	5 (11.1)	6 (31.6)	1 (2.2)	0 (0.0)

Behavioral problems			N/A				41 (91.1)	17 (89.5)	2 (4.4)	1 (5.3)	2 (4.4)	1 (5.3)
NOT recommended features												
Blood test for genetic studies	10 (3.9)	8 (10.0)	242 (94.2)	69 (86.3)	5 (1.9)	3 (3.8)	0 (0.0)	2 (10.5)	43 (95.6)	17 (89.5)	2 (4.4)	0 (0.0)
Brain scan	11 (4.3)	7 (8.8)	244 (94.9)	71 (88.8)	2 (0.8)	2 (2.5)	2 (4.4)	2 (10.5)	41 (91.1)	17 (89.5)	2 (4.4)	0 (0.0)

*Note. Has a high level of independence and Has some independence but needs support are considered as High support; Needs a high level of support in daily living and Needs high level institution-like are considered as Low support. N/A = Question was not presented to the respondent group. Recommended and NOT recommended features were retrieved from the National Institute for Health and Care Excellence (2012). The original questions were the following: autistic adult = Based on your experience, were the following factors part of your diagnostic evaluation for autism spectrum?; Carer = Were the following factors part of the adult's diagnostic evaluation for autism spectrum?; Professional = Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors part of the adult's diagnostic evaluation for autism spectrum in adults? Values expressed as number of responders and frequencies (in parenthesis).*

## Supplementary material 9

*Recommended and NOT recommended features for an adult diagnostic evaluation for autism spectrum by countries*

Answer	Autistic adults (N=354)				Carer (N=64)				Professional (N=143/144)					
	Yes	No	Do not know	Total	Yes	No	Do not know	Total	Standard routine practice	Not standard practice, but often considered	Rarely considered	Never considered	Do not know	Total
Recommended features														
n (%)		N		n (%)		N		n (%)		N				
Multidisciplinary team														
Denmark	47(30.3)	96 (61.9)	12 (7.7)	155	15 (46.9)	16 (50.0)	1 (3.1)	32	12 (52.2)	2 (8.7)	1 (4.4)	2 (8.7)	6 (26.1)	23
Finland	34 (70.8)	11 (22.9)	3 (6.3)	48	4 (100.0)	0	0	4	32 (80.0)	5 (12.5)	1 (2.5)	1 (2.5)	1 (2.5)	40
France	30 (65.2)	16 (34.8)	0	46	7 (58.3)	5 (41.7)	0	12	18 (66.7)	6 (22.2)	2 (7.4)	0	1 (3.7)	27
Spain	7 (43.8)	7 (43.8)	2 (12.4)	16	2 (50.0)	2 (50.0)	0	4	6 (42.9)	3 (21.4)	2 (14.3)	2 (14.3)	1 (7.4)	14
Italy	7 (58.3)	4 (33.3)	1 (8.3)	12	4 (100.0)	0	0	4	13 (65.0)	6 (30.0)	1 (5.0)	0	0	20
Poland	14 (63.6)	6 (27.3)	2 (9.1)	22	1 (100.0)	0	0	1	6 (75.0)	1 (12.5)	1 (12.5)	0	0	8
Iceland	4 (28.6)	7	3	14	1	2	0	3	2	1	0	0	1	4

		(50.0)	(21.4)		(33.3)	(66.7)			(50.0)	(25.0)			(25.0)	
United Kingdom	8 (40.0)	10 (50.0)	2 (10.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	3 (33.3)	6 (66.7)	0	9	1 (25.0)	3 (75.0)	0	4	0	0	0	0	0	0
German	2 (40.0)	3 (60.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	2

#### Close person asked about adult's symptoms

Denmark	109 (70.3)	41 (26.5)	5 (3.2)	155	24 (75.0)	8 (25.0)	0	32	9 (39.1)	6 (26.1)	2 (8.7)	0	6 (26.1)	23
Finland	33 (68.8)	14 (29.2)	1 (2.1)	48	4 (100.0)	0	0	4	31 (77.5)	8 (20.0)	0	0	1 (2.5)	40
France	23 (50.0)	23 (50.0)	0	46	8 (66.7)	4 (33.3)	0	12	21 (77.8)	3 (11.1)	1 (3.7)	0	2 (7.4)	27
Spain	8 (50.0)	8 (50.0)	0	16	4 (100.0)	0	0	4	12 (85.7)	2 (14.3)	0	0	0	14
Italy	8 (66.7)	4 (33.3)	0	12	4 (100.0)	0	0	4	18 (90.0)	1 (5.0)	0	0	1 (5.0)	20
Poland	16 (72.7)	6 (27.3)	0	22	1 (100.0)	0	0	1	4 (50.0)	3 (37.5)	1 (12.5)	0	0	8
Iceland	10 (71.4)	4 (28.6)	0	14	3 (100.0)	0	0	3	3 (75.0)	0	1 (25.0)	0	0	4
United Kingdom	11 (55.0)	9 (45.0)	0	20	0	0	0	0	6 (100.0)	0	0	0	0	6

Republic of Ireland	8 (88.9)	1 (11.1)	0	9	3 (75.0)	1 (25.0)	0	4	0	0	0	0	0	0
German	3 (60.0)	2 (40.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	0	2

Questionnaire on symptoms														
Denmark	103 (66.5)	45 (29.0)	7 (4.5)	155				N/A					N/A	
Finland	45 (93.7)	2 (4.2)	1 (2.1)	48				N/A					N/A	
France	28 (60.9)	18 (39.1)	0	46				N/A					N/A	
Spain	12 (75.0)	3 (18.8)	1 (6.2)	16				N/A					N/A	
Italy	10 (83.3)	2 (16.7)	0	12				N/A					N/A	
Poland	14 (63.6)	8 (36.4)	0	22				N/A					N/A	
Iceland	11 (78.6)	3 (21.4)	0	14				N/A					N/A	
United Kingdom	14 (70.0)	6 (30.0)	0	20				N/A					N/A	
Republic of Ireland	4 (44.4)	4 (44.4)	1 (11.1)	9				N/A					N/A	
German	4 (80.0)	1 (20.0)	0	5				N/A					N/A	



Function evaluated in different settings														
Denmark	143 (92.3)	7 (4.5)	5 (3.2)	155	31 (96.9)	1 (3.1)	0	32	16 (69.6)	2 (8.7)	0	0	5 (21.7)	23
Finland	44 (91.7)	3 (6.2)	1 (2.1)	48	3 (75.0)	0	1 (25.0)	4	13 (32.5)	10 (25.0)	6 (15.0)	5 (12.5)	6 (3.7)	40
France	41 (89.1)	4 (8.7)	1 (2.2)	46	7 (58.3)	5 (41.7)	0	12	21 (77.8)	4 (14.8)	0	1 (3.7)	1 (3.7)	27
Spain	15 (93.8)	0	1 (6.2)	16	4 (100.0)	0	0	4	13 (92.9)	0	1 (7.1)	0	0	14
Italy	12 (100.0)	0	0	12	3 (75.0)	1 (25.0)	0	4	16 (80.0)	2 (10.0)	1 (5.0)	0	1 (5.0)	20
Poland	22 (100.0)	0	0	22	1 (100.0)	0	0	1	5 (62.5)	3 (37.5)	0	0	0	8
Iceland	4 (28.6)	10 (71.4)	0	14	3 (100.0)	0	0	3	3 (75.0)	0	1 (25.0)	0	0	4
United Kingdom	19 (95.0)	1 (5.0)	0	20	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	7 (77.8)	0	2 (22.2)	9	4 (100.0)	0	0	4	0	0	0	0	0	0
German	5 (100.0)	0	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	2
Physical or mental problems														
Denmark	138 (89.0)	11 (7.1)	6 (3.9)	155	29 (90.6)	2 (6.3)	1 (3.1)	32	16 (69.6)	2 (8.7)	0	0	5 (21.7)	23

Finland	44 (91.7)	3 (6.2)	1 (2.1)	48	3 (75.0)	0	1 (25.0)	4	30 (75.0)	3 (7.5)	3 (7.5)	0	4 (10.0)	40
France	37 (80.4)	6 (13.0)	3 (6.6)	46	7 (58.3)	5 (41.7)	0	12	22 (81.5)	2 (7.4)	0	1 (3.7)	2 (7.4)	27
Spain	10 (62.5)	6 (37.5)	0	16	4 (100.0)	0	0	4	12 (85.7)	1 (7.1)	1 (7.1)	0	0	14
Italy	8 (66.7)	3 (25.0)	1 (8.3)	12	4 (100.0)	0	0	4	15 (75.0)	3 (15.0)	1 (5.0)	0	1 (5.0)	20
Poland	21 (95.5)	1 (4.5)	0	22	1 (100.0)	0	0	1						
									5 (62.5)	3 (37.5)	0	0	0	8
Iceland	8 (57.1)	4 (28.5)	2 (14.3)	14	2 (66.7)	0	1 (33.3)	3	3 (75.0)	1 (25.0)	0	0	0	4
United Kingdom	17 (85.0)	2 (10.0)	1 (5.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	5 (55.6)	0	4 (44.4)	9	4 (100.0)	0	0	4	0	0	0	0	0	0
German	4 (80.0)	0	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	0	2

#### Development problems like ADHD

Denmark	120 (77.4)	26 (16.8)	9 (5.8)	155	28 (87.5)	4 (12.5)	0	32	10 (43.5)	5 (21.7)	0	0	8 (34.8)	23
Finland	39 (81.3)	7 (14.6)	2 (4.2)	48	4 (100.0)	0	0	4	31 (77.5)	6 (15.0)	0	0	3 (7.5)	40

France	36 (78.3)	7 (15.2)	3 (6.5)	46	7 (58.3)	5 (41.7)	0	12	24 (88.9)	1 (3.7)	0	2 (7.4)	0	27
Spain	10 (62.5)	4 (25.0)	2 (12.5)	16	4 (100.0)	0	0	4	12 (85.7)	2 (14.3)	0	0	0	14
Italy	10 (83.3)	2 (16.7)	0	12	4 (100.0)	0	0	4	13 (65.0)	4 (20.0)	1 (5.0)	0	2 (10.0)	20
Poland	18 (81.8)	3 (13.6)	1 (4.6)	22	1 (100.0)	0	0	1	5 (62.5)	3 (37.5)	0	0	0	8
Iceland	7 (50.0)	4 (28.6)	3 (21.4)	14	3 (100.0)	0	0	3	4 (100.0)	0	0	0	0	4
United Kingdom	14 (70.0)	3 (15.0)	3 (15.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	3 (33.3)	2 (22.2)	4 (44.4)	9	4 (100.0)	0	0	4	0	0	0	0	0	0
German	4 (80.0)	0	1 (20.0)	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	2

#### Language/communication difficulties

Denmark	135 (87.1)	14 (9.0)	6 (3.9)	155	30 (93.8)	2 (6.2)	0	32	18 (78.3)	1 (4.4)	0	0	4 (17.4)	23
Finland	41 (85.4)	6 (12.5)	1 (2.1)	48	4 (100.0)	0	0	4	31 (77.5)	5 (12.5)	2 (5.0)	0	2 (5.0)	40
France	40 (87.0)	5 (10.9)	1 (2.2)	46	10 (83.3)	2 (16.7)	0	12	21 (77.8)	3 (11.1)	0	1 (3.7)	2 (7.4)	27
Spain	13	3	0	16	4	0	0	4	13	1 (7.1)	0	0	0	14

	(81.3)	(18.7)			(100.0)				(92.9)					
Italy	11 (91.7)	1 (8.3)	0	12	4 (100.0)	0	0	4	15 (75.0)	2 (10.0)	2 (10.0)	0	1 (5.0)	20
Poland	21 (95.5)	1 (4.5)	0	22	1 (100.0)	0	0	1	6 (75.0)	2 (25.0)	0	0	0	8
Iceland	10 (71.4)	1 (7.1)	3 (21.4)	14	3 (100.0)	0	0	3	3 (75.0)	1 (25.0)	0	0	0	4
United Kingdom	18 (90.0)	1 (5.0)	1 (5.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	0
Republic of Ireland	4 (44.4)	2 (22.2)	3 (33.4)	9	4 (100.0)	0	0	4	0	0	0	0	0	0
German	4 (80.0)	1 (20.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	0

#### Sensory problems

Denmark	123 (79.4)	23 (14.8)	9 (5.8)	155	22 (68.8)	7 (21.8)	3 (9.4)	32	9 (39.1)	5 (21.7)	1 (4.4)	1 (4.4)	7 (30.4)	23
Finland	43 (89.6)	4 (8.3)	1 (2.1)	48	2 (50.0)	0	2 (50.0)	4	27 (67.5)	5 (12.5)	1 (2.5)	3 (7.5)	4 (10.0)	40
France	41 (89.1)	4 (8.7)	1 (2.2)	46	8 (66.7)	4 (33.3)	0	12	18 (66.7)	7 (25.9)	0	1 (3.7)	1 (3.7)	27
Spain	11 (68.8)	5 (31.2)	0	16	4 (100.0)	0	0	4	11 (78.6)	1 (7.1)	2 (14.2)	0	0	14
Italy	12 (100.0)	0	0	12	4 (100.0)	0	0	4	13 (65.0)	3 (15.0)	3 (15.0)	0	1 (5.0)	20

Poland	21 (95.5)	0	1 (4.5)	22	1 (100.0)	0	0	1	5 (62.5)	2 (25.0)	1 (12.5)	0	0	8
Iceland	6 (42.9)	6 (42.9)	2 (14.3)	14	2 (66.7)	0	1 (33.3)	3	1 (25.0)	2 (50.0)	0	0	1 (25.0)	4
United Kingdom	18 (90.0)	2 (10.0)	0	20	0	0	0	0	5 (83.3)	1 (16.7)	0	0	0	6
Republic of Ireland	6 (66.7)	2 (22.2)	1 (11.1)	9	3 (75.0)	1 (25.0)	0	4	0	0	0	0	0	0
German	4 (80.0)	0	1 (20.0)	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	0	1 (50.0)	0	0	2

#### Self-harm or harm to others

Denmark	92 (59.4)	49 (31.6)	14 (9.0)	155	24 (75.0)	6 (18.8)	2 (6.2)	32	13 (56.5)	3 (13.0)	0	0	7 (30.4)	23
Finland	27 (56.2)	13 (27.1)	8 (16.7)	48	2 (50.0)	0	2 (50.0)	4	29 (72.5)	6 (15.0)	2 (5.0)	0	3 (7.5)	40
France	24 (52.2)	18 (39.1)	4 (8.7)	46	9 (75.0)	3 (25.0)	0	12	16 (59.3)	9 (33.3)	1 (3.7)	0	1 (3.7)	27
Spain	9 (56.3)	3 (18.7)	4 (25.0)	16	3 (75.0)	1 (25.0)	0	4	12 (85.7)	2 (14.3)	0	0	0	14
Italy	8 (66.7)	4 (33.3)	0	12	4 (100.0)	0	0	4	16 (80.0)	3 (15.0)	0	0	1 (5.0)	20
Poland	12 (54.6)	7 (31.8)	3 (13.6)	22	1 (100.0)	0	0	1	4 (50.0)	3 (37.5)	1 (12.5)	0	0	8
Iceland	6 (42.9)	6	2	14	2	1	0	3	2	2 (50.0)	0	0	0	4

		(42.9)	(14.3)		(66.7)	(33.3)		(50.0)						
United Kingdom	9 (45.0)	7 (35.0)	4 (20.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	3 (33.3)	4 (44.4)	2 (22.2)	9	3 (75.0)	1 (25.0)	0	4	0	0	0	0	0	0
German	2 (40.0)	1 (20.0)	2 (40.0)	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	0	2

**Being abused/ neglected or taken advantage of**

Denmark	63 (40.6)	71 (45.8)	21 (13.6)	155	12 (37.5)	13 (40.6)	7 (21.9)	32	9 (39.1)	4 (17.4)	0	0	10 (43.5)	23
Finland	17 (35.4)	24 (50.0)	7 (14.6)	48	2 (50.0)	0	2 (50.0)	4	24 (60.0)	8 (20.09)	2 (5.0)	1 (2.5)	5 (12.5)	40
France	24 (52.2)	19 (41.3)	3 (6.5)	46	5 (41.7)	6 (50.0)	1 (8.3)	12	5 (18.5)	10 (37.0)	4 (14.8)	2 (7.4)	6 (22.2)	27
Spain	6 (37.5)	6 (37.5)	4 (25.0)	16	0	4 (100.0)	0	4	5 (38.5)	6 (46.2)	2 (15.4)	0	0	13
Italy	5 (41.7)	7 (58.3)	0	12	3 (75.0)	0	1 (25.0)	4	6 (30.0)	7 (35.0)	2 (10.0)	2 (10.0)	3 (15.0)	20
Poland	9 (40.9)	12 (54.6)	1 (4.5)	22	1 (100.0)	0	0	1	2 (25.0)	5 (62.5)	0	1 (12.5)	0	8
Iceland	4 (28.6)	6 (42.9)	4 (28.6)	14	2 (66.7)	0	1 (33.3)	3	1 (25.0)	1 (25.0)	0	0	2 (50.0)	4
United Kingdom	9 (45.0)	9 (45.0)	2 (10.0)	20	0	0	0	0	6 (100.0)	0	0	0	0	0

Republic of Ireland	2 (22.2)	4 (44.4)	3 (33.3)	9	2 (50.0)	2 (50.0)	0	4	0	0	0	0	0	0
German	2 (40.0)	3 (60.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	0

Denmark	29 (18.7)	103 (66.5)	23 (14.8)	155		3 (9.4)	18 (56.2)	11 (34.4)	32		1 (4.4)	2 (8.7)	4 (17.4)	3 (13.0)	13 (56.5)	23
Finland	9 (18.8)	29 (60.4)	10 (20.8)	48		1 (25.0)	1 (25.0)	2 (50.0)	4		10 (25.0)	6 (15.0)	12 (30.0)	2 (5.0)	10 (25.0)	40
France	8 (17.4)	36 (78.3)	2 (4.3)	46		1 (8.33)	10 (83.3)	1 (8.3)	12		1 (3.7)	6 (22.2)	8 (29.6)	3 (11.1)	9 (33.3)	27
Spain	2 (12.5)	13 (81.3)	1 (6.2)	16		0	4 (100.0)	0	4		1 (7.7)	5 (38.5)	6 (46.2)	0	1 (7.7)	13
Italy	2 (16.7)	10 (83.3)	0	12		0	4 (100.0)	0	4		5 (25.0)	6 (30.0)	2 (10.0)	3 (15.0)	4 (20.0)	20
Poland	8 (36.4)	13 (59.1)	1 (4.5)	22		0	1 (100.0)	0	1		0	4 (50.0)	3 (37.5)	1 (12.5)	0	8
Iceland	3 (21.4)	10 (71.4)	1 (7.2)	14		1 (33.3)	1 (33.3)	1 (33.3)	3		1 (25.0)	1 (25.0)	0	1 (25.0)	1 (25.0)	4
United Kingdom	3 (15.0)	15 (75.0)	2 (10.0)	20		0	0	0	0		6 (100.0)	0	0	0	0	0
Republic of Ireland	1 (11.1)	6 (66.7)	2 (22.2)	9		2 (50.0)	2 (50.0)	0	4		0	0	0	0	0	0
German	0	4 (80.0)	1 (20.0)	5		0	0	0	0		0	0	0	0	0	0

Portugal	0	0	0	0	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	2
<b>Adult's development</b>														
Denmark	N/A			28 (87.5)	3 (9.4)	1 (3.1)	32		12 (52.2)	4 (17.4)	0	2 (8.7)	5 (21.7)	23
Finland	N/A			4 (100.0)	0	0	4		35 (87.5)	3 (7.5)	0	0	2 (5.0)	40
France	N/A			6 (50.0)	6 (50.0)	0	12		25 (92.6)	0	1 (3.7)	0	1 (3.7)	27
Spain	N/A			4 (100.0)	0	0	4		11 (84.6)	2 (15.4)	0	0	0	13
Italy	N/A			3 (75.0)	1 (25.0)	0	4		15 (75.0)	2 (10.0)	0	0	3 (15.0)	20
Poland	N/A			1 (100.0)	0	0	1		5 (62.5)	3 (37.5)	0	0	0	8
Iceland	N/A			3 (100.0)	0	0	3		3 (75.0)	1 (25.0)	0	0	0	4
United Kingdom	N/A			0	0	0	0		6 (100.0)	0	0	0	0	6
Republic of Ireland	N/A			3 (75.0)	1 (25.0)	0	4		0	0	0	0	0	0
German	N/A			0	0	0	0		0	0	0	0	0	0
Portugal	N/A			0	0	0	0		1 (50.0)	1 (50.0)	0	0	0	2



Behavioral problems											
Denmark	N/A	30 (93.8)	0	2 (6.2)	32	18 (78.3)	1 84.4)	0	0	1 (5.0)	23
Finland	N/A	3 (75.0)	0	1 (25.0)	4	31 (77.5)	5 (12.5)	2 (5.0)	0	2 (5.0)	40
France	N/A	10 (83.3)	2 (16.7)	0	12	21 (77.8)	5 (18.5)	0	0	1 (3.7)	27
Spain	N/A	4 (100.0)	0	0	4	12 (92.3)	0	1 (7.7)	0	0	13
Italy	N/A	4 (100.0)	0	0	4	17 (85.0)	2 (10.0)	0	0	1 (5.0)	20
Poland	N/A	1 (100.0)	0	0	1	5 (62.5)	3 (37.5)	0	0	0	8
Iceland	N/A	2 (66.7)	1 (33.3)	0	3	3 (75.0)	1 (25.0)	0	0	0	4
United Kingdom	N/A	0	0	0	0	6 (100.0)	0	0	0	0	6
Republic of Ireland	N/A	4 (100.0)	0	0	4	0	0	0	0	0	0
German	N/A	0	0	0	0	0	0	0	0	0	0
Portugal	N/A	0	0	0	0	2 (100.0)	0	0	0	0	2
NOT recommended features for a routine evaluation											

Blood test for genetic studies														
Denmark	1 (0.7)	151 (97.4)	3 (1.9)	155	0	31 (96.9)	1 (3.1)	32	1 (4.4)	4 (17.4)	4 (17.4)	3 (13.0)	11 (47.8)	23
Finland	1 (2.1)	43 (89.6)	4 (8.3)	48	0	3 (75.0)	1 (25.0)	4	2 (5.0)	6 (15.0)	9 (22.5)	12 (30.0)	11 (27.5)	40
France	8 (17.4)	38 (82.6)	0	46	1 (8.3)	11 (91.7)	0	12	7 (25.9)	10 (37.0)	4 (14.8)	3 (11.1)	3 (11.1)	27
Spain	2 (12.5)	14 (87.5)	0	16	0	4 (100.0)	0	4	1 (7.7)	7 (53.9)	4 (30.8)	1 (7.7)	0	13
Italy	1 (8.3)	11 (91.7)	0	12	1 (25.0)	3 (75.0)	0	4	8 (40.0)	6 (30.0)	4 (20.0)	0	2 (10.0)	20
Poland	1 (4.6)	21 (95.4)	0	22	0	1 (100.0)	0	1	0	3 (37.5)	5 (62.5)	0	0	8
Iceland	1 (7.1)	11 (78.6)	2 (14.3)	14	0	3 (100.0)	0	3	0	1 (25.0)	0	1 (25.0)	2 (50.0)	4
United Kingdom	2 (10.0)	18 (90.0)	0	20	0	0	0	0	0	0	3 (50.0)	2 (33.3)	1 (16.7)	6
Republic of Ireland	1 (11.1)	8 (88.9)	0	9	0	4 (100.0)	0	4	0	0	0	0	0	0
German	0	5 (100.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	2
Brain scan														
Denmark	3 (1.9)	149 (96.1)	3 (1.9)	155	1 (3.1)	30 (93.8)	1 (3.1)	32	1 (4.4)	4 (17.4)	4 (17.4)	3 (13.0)	11 (47.8)	23

Finland	3 (6.2)	44 (91.7)	1 (2.1)	48	0	3 (75.0)	1 (25.0)	4	7 (17.5)	5 (12.5)	15 (37.5)	4 (10.0)	9 (22.5)	40
France	5 (10.9)	41 (89.1)	0	46	1 (8.3)	11 (91.7)	0	12	4 (14.8)	8 (29.6)	7 (25.9)	4 (14.8)	4 (14.8)	27
Spain	2 (12.5)	14 (87.5)	0	16	1 (25.0)	3 (75.0)	0	4	2 (15.4)	6 (46.2)	4 (30.8)	1 (7.7)	0	13
Italy	1 (8.3)	11 (91.7)	0	12	0	4 (100.0)	0	4	7 (35.0)	4 (20.0)	2 (10.0)	1 (5.0)	6 (30.0)	20
Poland	4 (18.2)	18 (81.8)	0	22	1 (100.0)	0	0	1	2 (25.0)	0	5 (62.5)	1 (12.5)	0	8
Iceland	0	14 (100.0)	0	14	0	3 (100.0)	0	3	1 (25.0)	1 (25.0)	0	0	2 (50.0)	4
United Kingdom	1 (5.0)	19 (95.0)	0	20	0	0	0	0	0	0	3 (50.0)	2 (33.3)	1 (16.7)	6
Republic of Ireland	0	9 (100.0)	0	9	0	4 (100.0)	0	4	0	0	0	0	0	0
German	0	5 (100.0)	0	5	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	0

*Note.* Recommended and NOT recommended features were retrieved from the National Institute for Health and Care Excellence (2012).

N/A=Question was not presented to the respondent group. The questions were the following: autistic adult=*Based on your experience, were the following factors part of your diagnostic evaluation for autism spectrum?*; Carer=*Were the following factors part of the adult's diagnostic*

*evaluation for autism spectrum?; Professional=Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors part of the adult's diagnostic evaluation for autism spectrum in adults?.*

## Supplementary material 10

*Recommended and NOT recommended features for a routine adult diagnostic evaluation for autism spectrum. Analysis removing adult and carer respondents who reported the adult's autism diagnosis at a time before the 2012 publication of NICE guidelines.*

Answer	Autistic adult (N=333)			Carer (N=58)		
	Recommended features					
	Yes	No	Do not know	Yes	No	Do not know
	<i>n (%)</i>			<i>n (%)</i>		
Multidisciplinary team	147 (44.1)	161 (48.4)	25 (7.5)	31 (53.5)	26 (44.8)	1 (1.7)
Close person asked about adult’s symptoms	219 (65.8)	108 (32.4)	6 (1.8)	46 (79.3)	12 (20.7)	0
Questionnaire on symptoms	235 (70.6)	89 (26.7)	9 (2.7)	N/A		
Function evaluated in different settings	300 (90.1)	23 (6.9)	10 (3.0)	51 (87.9)	7 (12.1)	0
Physical or mental problems	282 (84.7)	32 (9.6)	19 (5.7)	48 (82.8)	7(12.1)	3 (5.2)

Development problems like ADHD	252 (75.7)	55 (16.5)	26 (7.8)	50 (86.2)	8 (13.8)	0
Language / communication difficulties	286 (85.9)	33 (9.9)	14 (4.2)	54 (93.1)	4 (6.9)	0
Sensory problems	275 (82.6)	43 (12.9)	15 (4.5)	42 (72.4)	11 (19.0)	5 (8.6)
Self-harm or harm to others	185 (55.6)	107 (32.1)	41 (12.3)	43 (74.1)	12 (20.7)	3 (5.2)
Being abused / neglected or taken advantage of	133 (39.9)	157 (47.2)	43 (12.9)	26 (44.8)	23 (39.7)	9 (15.5)
Contact with the police	63 (18.9)	228 (68.5)	42 (12.6)	8 (13.8)	37 (63.8)	13 (22.4)
Adult's development	N/A			47 (81.0)	10 (17.2)	1 (1.8)
Behavioral problems	N/A			53 (91.4)	3 (5.2)	2 (3.4)
Consultation with other experts	N/A			N/A		
Core autistic behaviors	N/A			N/A		
Direct observation	N/A			N/A		

Standard tests for autism	N/A			N/A		
Standard tests for cognitive or psychological functioning	N/A			N/A		
Physical examination	N/A			N/A		
NOT recommended features for a routine evaluation						
Blood test for genetic studies	13 (3.9)	312 (93.7)	8 (2.4)	2 (3.5)	55 (94.8)	1 (1.7)
Brain scan	16 (4.8)	313 (94.0)	4 (1.2)	4 (6.9)	54 (93.1)	0
Biological tests	N/A			N/A		

*Note.* Recommended and NOT recommended features for a routine evaluation were retrieved from the National Institute for Health and Care Excellence (2012). N/A=Question was not presented to the respondent group. The questions were the following: autistic adult=*Based on your experience, were the following factors part of your diagnostic evaluation for autism spectrum?*; Carer=*Were the following factors part of the adult's diagnostic evaluation for autism spectrum?*; Professional=*Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors part of the adult's diagnostic evaluation for autism spectrum in adults?*.

## Supplementary material 11

*Number of recommended features for autistic adult post-diagnosis support reported by responders*

Number of recommendations	Autistic adult (N=344)	Carer (N=64)	Professional (N=139)
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
0	229 (66.6)	30 (46.9)	23 (16.6)
1	80 (23.3)	15 (23.4)	14 (10.1)
2	27 (7.9)	12 (18.8)	17 (12.2)
3	7 (2.0)	5 (7.8)	9 (6.5)
4	1 (0.3)	1 (1.6)	14 (10.1)
5		1 (1.6)	33 (23.7)
6			29 (20.9)



**Supplementary material 12**

*Stratified results of information on recommended features for autistic adult post-diagnosis support by autistic adults' gender, high/some independence and high level of support/institution-like care of the autistic adult cared reported by carers*

Answer	Autistic adult (N = 334)						Carer (N = 64)					
	Female	Male	Female	Male	Female	Male	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care	High or some independ ence	High- level of support or institutio n-like care
	Yes		No		Do not know		Yes		No		Do not know	
Written recommendatio ns for care and follow-up for non-medical problems	45 (17.6)	18 (23.1)	196 (76.6)	50 (64.1)	15 (5.9)	10 (12.8)	19 (42.2)	3 (15.8)	23 (51.1)	15 (78.9)	3 (6.7)	1 (5.3)
Written recommendatio ns for health care	39 (15.2)	12 (15.4)	199 (77.7)	60 (76.9)	18 (7.0)	6 (7.7)	6 (13.3)	2 (10.5)	35 (77.8)	15 (78.9)	4 (8.9)	2 (10.5)
'Health passport' to carry important information about the adult needs and care	2 (0.8)	3 (3.9)	134 (91.4)	70 (89.8)	20 (7.8)	5 (6.4)	4 (8.9)	1 (5.3)	37 (82.2)	17 (89.5)	4 (8.9)	1 (5.3)

Referral for specialist care for health or medical problems	28 (10.9)	12 (15.4)	209 (81.6)	61 (78.2)	19 (7.4)	5 (6.4)	17 (37.8)	3 (15.8)	26 (57.8)	16 (84.2)	2 (4.4)	0 (0.0)
Written recommendations for how to manage a crisis			N/A				3 (6.7)	2 (10.5)	37 (82.2)	15 (78.9)	5 (11.1)	2 (10.5)
Written recommendations for managing risks			N/A				3 (6.7)	0 (0.0)	31 (68.9)	18 (94.7)	11 (24.4)	1 (5.3)

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*Note.* N/A = Question was not presented to the respondent group. *No, but it was needed* and *No, and it was NOT needed* are considered as NO.

The original questions were the following: autistic adult = *After you got the autism spectrum diagnosis, which of the following things happened?*; Carer = *After the adult got the autism spectrum diagnosis, which of the following things happened?*; Professional = *Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors considered as parts of the post-diagnostic activities for autistic adults?* Values expressed as number of responders and frequencies (in parenthesis).

**Supplementary material 13***Recommended features for autistic adult post-diagnosis support by countries*

Answer	Autistic adult (N=344)					Carer (N=64)					Professional (N=139)								
	Yes	No, but it was needed	No and it was not needed	Do not know	Total	Yes	No, but it was needed	No and it was not needed	Do not know	Total	Standard routine practice	Not standard practice, but often considered	Rarely considered	Never considered	Do not know	Total			
	n (%)					N					n (%)					N			
Written recommendations for care and follow-up for non-medical problems																			
Denmark	26 (16.9)	94 (61.0)	22 (14.3)	12 (7.8)	154	8 (25.0)	20 (62.5)	1 (3.1)	3 (9.4)	32	10 (47.6)	3 (14.3)	1 (4.8)	0	7 (33.3)	21			
Finland	3 (6.2)	36 (75.0)	8 (16.7)	1 (2.1)	48	0	3 (75.0)	0	1 (25.0)	4	9 (23.1)	7 (18.0)	8 (20.5)	2 (5.1)	13 (33.3)	39			
France	12 (26.7)	19 (42.2)	10 (22.2)	4 (8.9)	45	6 (50.0)	5 (41.7)	1 (8.3)	0	12	22 (81.5)	2 (7.4)	0	0	3 (11.1)	27			
Spain	4 (25.0)	5 (31.2)	7 (43.8)	0	16	3 (75.0)	1 (25.0)	0	0	4	6 (46.2)	6 (46.2)	1 (7.7)	0	0	13			
Italy	2 (16.7)	1 (8.3)	6 (50.0)	3 (25.0)	12	2 (50.0)	2 (50.0)	0	0	4	11 (57.9)	5 (26.3)	1 (5.3)	1 (5.3)	1 (5.3)	19			
Poland	4 (18.2)	7 (31.8)	11 (50.0)	0	22	1 (100.0)	0	0	0	1	5 (62.5)	3 (37.5)	0	0	0	8			
Iceland	0	7 (53.8)	5 (38.5)	1 (7.7)	13	0	2 (66.7)	1 (33.3)	0	3	1 (25.0)	0	1 (25.0)	1 (25.0)	1 (25.0)	4			

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United Kingdom	4 (20.0)	11 (55.0)	2 (10.0)	3 (15.0)	20	0	0	0	0	0	6 (100.0)	0	0	0	0	0
Republic of Ireland	6 (66.7)	1 (11.1)	0	2 (22.2)	9	2 (50.0)	2 (50.0)	0	0	4	0	0	0	0	0	0
German	2 (40.0)	1 (20.0)	2 (40.0)	0	5	0	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	0	0

## Written recommendations for health care

Denmark	18 (11.7)	89 (57.8)	34 (22.1)	13 (8.4)	154	3 (9.4)	21 (65.6)	5 (15.6)	3 (9.4)	32	6 (28.6)	2 (9.5)	2 (9.5)	0	11 (52.3)	21
Finland	6 (12.5)	33 (68.7)	7 (14.6)	2 (4.2)	48	0	1 (25.0)	0	3 (75.0)	4	7 (17.9)	13 (33.3)	8 (20.5)	2 (5.1)	9 (23.1)	39
France	11 (24.4)	19 (42.2)	13 (28.9)	2 (4.4)	45	3 (25.0)	6 (50.0)	3 (25.0)	0	12	16 (56.3)	7 (25.9)	0	0	4 (14.8)	27
Spain	1 (6.2)	7 (43.8)	6 (37.5)	2 (12.5)	16	0	2 (50.0)	2 (50.0)	0	4	4 (30.7)	7 (53.9)	2 (15.4)	0	0	13
Italy	1 (8.3)	1 (8.3)	9 (75.0)	1 (8.3)	12	0	2 (50.0)	2 (50.0)	0	4	9 (47.4)	6 (31.6)	2 (10.5)	0	2 (10.5)	19
Poland	4 (18.2)	7 (31.8)	11 (50.0)	0	22	1 (100.0)	0	0	0	1	1 (12.5)	6 (75.0)	1 (12.5)	0	0	8
Iceland	2 (15.4)	6 (46.1)	4 (30.8)	1 (7.7)	13	0	2 (66.7)	1 (33.3)	0	3	0	0	1 (25.0)	1 (25.0)	2 (50.0)	4
United Kingdom	2 (10.0)	10 (50.0)	7 (35.0)	1	20	0	0	0	0	0	4 (66.7)	1 (16.7)	1 (16.7)	0	0	6
Republic of	4 (44.4)	1 (11.1)	2 (22.2)	2 (22.2)	9	1 (25.0)	3 (75.0)	0	0	4	0	0	0	0	0	0

Ireland

German	2 (40.0)	2 (40.0)	1 (20.0)	0	5	0	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	0	0	0	2 (100.0)	0	0	0	2

**Health passport to carry important information about the adult needs and care**

Denmark	1 (0.6)	99 (64.3)	40 (26.0)	14 (9.1)	154	2 (6.2)	26 (81.3)	2 (6.2)	2 (6.2)	32	1 (4.8)	2 (9.5)	3 (14.3)	2 (9.5)	13 (61.9)	21
Finland	0	33 (68.7)	13 (27.1)	2 (4.2)	48	1 (25.0)	2 (50.0)	0	1 (25.0)	4	1 (2.6)	4 (10.3)	10 (25.6)	9 (23.1)	15 (38.5)	39
France	2 (4.4)	32 (71.1)	8 (17.8)	3 (6.7)	45	1 (8.3)	8 (66.7)	1 (8.3)	2 (16.7)	12	2 (7.4)	6 (22.2)	5 (18.5)	11 (40.7)	3 (11.1)	27
Spain	0	10 (62.5)	5 (31.2)	1 (6.3)	16	0	0	4 (100.0)	0	4	2 (15.4)	2 (15.4)	6 (46.2)	3 (23.1)	0	13
Italy	0	5 (41.7)	6 (50.0)	1 (8.3)	12	0	4 (100.0)	0	0	4	0	4 (21.1)	5 (26.3)	8 (42.1)	2 (10.5)	19
Poland	0	6 (27.3)	16 (72.7)	0	22	0	0	1 (100.0)	0	1	1 (12.5)	3 (37.5)	2 (25.0)	2 (25.0)	0	8
Iceland	0	4 (30.8)	9 (69.2)	0	13	0	1 (33.3)	2 (66.6)	0	3	0	0	0	2 (50.0)	2 (50.0)	4
United Kingdom	1 (5.0)	10 (50.0)	7 (35.0)	2 (10.0)	20	0	0	0	0	0	3 (50.0)	0	2 (33.3)	1 (16.7)	0	6
Republic of Ireland	1 (11.1)	6 (66.7)	1 (11.1)	1 (11.1)	9	1 (25.0)	3 (75.0)	0	0	4	0	0	0	0	0	0
German	0	0	4 (80.0)	1 (20.0)	5	0	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	2

al											(50.0)	(50.0)						
Referral for specialist care for health or medical problems																		
Denmark	17 (11.0)	85 (55.2)	43 (27.9)	9 (5.8)	154		6 (18.7)	18 (56.3)	7 (21.9)	1 (3.1)	32		5 (23.8)	5 (23.8)	1 (4.8)	1 (4.8)	9 (42.9)	21
Finland	8 (16.7)	29 (60.4)	10 (20.8)	1 (2.1)	48		1 (25.0)	2 (50.0)	0	1 (25.0)	4		15 (38.5)	10 (25.6)	8 (20.5)	0	6 (15.4)	39
France	8 (17.8)	20 (44.4)	13 (28.9)	4 (8.9)	45		4 (33.3)	7 (58.3)	1 (8.3)	0	12		13 (48.2)	6 (22.2)	2 (7.4)	2 (7.4)	4 (14.8)	27
Spain	2 (12.5)	6 (37.5)	7 (43.8)	1 (6.2)	16		3 (75.0)	0	1 (25.0)	0	4		6 (46.2)	6 (46.2)	1 (7.7)	0	0	13
Italy	0	3 (25.0)	8 (66.7)	1 (8.3)	12		2 (50.0)	1 (25.0)	1 (25.0)	0	4		9 (47.4)	7 (36.8)	2 (10.5)	0	1 (5.3)	19
Poland	3 (13.6)	7 (31.8)	11 (50.0)	1 (4.6)	22		1 (100.0)	0	0	0	1		2 (25.0)	4 (50.0)	2 (25.0)	0	0	8
Iceland	0	5 (38.5)	5 (38.5)	3 (23.1)	13		2 (66.7)	1 (33.3)	0	0	3		0	2 (50.0)	0	0	2 (50.0)	4
United Kingdom	1 (5.0)	11 (55.0)	7 (35.0)	1 (5.0)	20		0	0	0	0	0		5 (83.3)	1 (16.7)	0	0	0	6
Republic of Ireland	1 (11.1)	4 (44.4)	2 (22.2)	2 (22.2)	9		1 (25.0)	3 (75.0)	0	0	4		0	0	0	0	0	0
Germany	0	1 (20.0)	3 (60.0)	1 (20.0)	5		0	0	0	0	0		0	0	0	0	0	0
Portugal	0	0	0	0	0		0	0	0	0	0		2 (100.0)	0	0	0	0	2
Written recommendations for how to manage a crisis																		
Denmark	N/A						0	23	6	3 (9.4)	32		4	5	1 (4.8)	0	11	21

k			(71.9)	(18.7)			(19.1)	(23.8)		(52.4)		
Finland	N/A	0	1 (25.0)	0	3 (75.0)	4	4 (10.3)	8 (20.6)	12 (30.8)	2 (5.1)	13 (33.3)	39
France	N/A	4 (33.3)	5 (41.7)	3 (25.0)	0	12	7 (25.9)	8 (29.6)	5 (18.5)	1 (3.7)	6 (22.2)	27
Spain	N/A	1 (25.0)	2 (50.0)	1 (25.0)	0	4	6 (46.2)	4 (30.8)	3 (23.1)	0	0	13
Italy	N/A	0	3 (75.0)	1 (25.0)	0	4	11 (57.9)	3 (15.8)	3 (15.8)	0	2 (10.5)	19
Poland	N/A	0	1 (100.0)	0	0	1	0	6 (75.0)	2 (25.0)	0	0	8
Iceland	N/A	0	1 (33.3)	2 (66.7)	0	3	0	0	1 (25.0)	1 (25.0)	2 (50.0)	4
United Kingdom	N/A	0	0	0	0	0	2 (33.3)	3 (50.0)	1 (16.7)	0	0	6
Republic of Ireland	N/A	0	3 (75.0)	0	1 (25.0)	4	0	0	0	0	0	0
German	N/A	0	0	0	0	0	0	0	0	0	0	0
Portugal	N/A	0	0	0	0	0	2 (100.0)	0	0	0	0	2

**Written recommendations for managing risks**

Denmark	N/A	8 (6.2)	14 (43.8)	7 (21.9)	9 (28.1)	32	7 (33.3)	2 (9.5)	1 (4.8)	0	11 (52.4)	21
Finland	N/A	0	3 (75.0)	0	1 (25.0)	4	4 (10.3)	8 (20.5)	9 (23.1)	2 (5.1)	16 (41.0)	39
France	N/A	0	7	4	1	12	12	7	3	0	5	27

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			(58.3)	(33.3)	(8.33)		(44.4)	(25.9)	(11.1)		(18.5)	
Spain	N/A	0	1 (25.0)	3 (75.0)	0	4	4 (30.8)	6 (46.2)	3 (23.1)	0	0	13
Italy	N/A	0	3 (75.0)	1 (25.0)	0	4	8 (42.1)	5 (26.3)	3 (17.8)	1 (5.3)	2 (10.5)	19
Poland	N/A	0	0	1 (100.0)	0	1	2 (25.0)	5 (62.5)	1 (12.5)	0	0	8
Iceland	N/A	0	1 (33.3)	2 (66.7)	0	3	0	0	1 (25.0)	1 (25.0)	2 (50.0)	4
United Kingdom	N/A	0	0	0	0	0	3 (50.0)	3 (50.0)	0	0	0	6
Republic of Ireland	N/A	1 (25.0)	2 (50.0)	0	1 (25.0)	4	0	0	0	0	0	0
German	N/A	0	0	0	0	0	0	0	0	0	0	0
Portugal	N/A	0	0	0	0	0	1 (50.0)	1 (50.0)	0	0	0	2



**Supplementary material 14**

*Recommended features for autistic adult post-diagnosis support. Analysis removing adult and carer respondents who reported the adult's autism diagnosis at a time before the 2012 publication of NICE guidelines.*

Answer	Autistic adult (N=331)				Carer (N=58)			
	Yes	No, but it was needed	No and it was not needed	Do not know	Yes	No, but it was needed	No and it was not needed	Do not know
Written recommendations for care and follow-up for non-medical problems	61 (18.4)	175 (52.9)	70 (21.2)	25 (7.6)	20 (34.5)	32 (55.2)	3 (5.2)	3 (5.2)
Written recommendations for health care	49 (14.8)	168 (50.8)	90 (27.2)	24 (7.2)	8 (13.8)	34 (58.6)	12 (20.7)	4 (6.9)
'Health passport' to carry important information about the adult needs and care	5 (1.5)	197 (59.5)	105 (31.7)	24 (7.3)	4 (6.9)	41 (70.7)	9 (15.5)	4 (6.9)
Referral for specialist care for health or medical problems	36 (10.9)	168 (50.8)	103 (31.1)	24 (7.2)	17 (29.3)	30 (51.7)	10 (17.2)	1 (1.7)

Written recommendations for how to manage a crisis	N/A	5 (8.6)	35 (60.3)	13 (22.4)	5 (8.6)
Written recommendations for managing risks	N/A	3 (5.2)	28 (48.3)	16 (27.6)	11 (19.0)

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*Note.* Values expressed as number of responders and frequencies (in parenthesis). N/A=Question was not presented to the respondent group. The questions were the following: autistic adult=*After you got the autism spectrum diagnosis, which of the following things happened?*; Carer=*After the adult got the autism spectrum diagnosis, which of the following things happened?*; Professional=*Thinking of the adult diagnostic service for autism spectrum that you know best, how often are the following factors considered as parts of the post-diagnostic activities for autistic adults?*.