



Early Detection, Diagnosis and Intervention Services for Young Children with Autism Spectrum Disorder in the European Union (ASDEU): Family and Professional Perspectives

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Abstract

Early services for ASD need to canvas the opinions of both parents and professionals. These opinions are seldom compared in the same research study. This study aims to ascertain the views of families and professionals on early detection, diagnosis and intervention services for young children with ASD. An online survey compiled and analysed data from 2032 respondents across 14 European countries (60.9% were parents; 39.1% professionals). Using an ordinal scale from 1 to 7, parents' opinions were more negative (mean = 4.6; SD 2.2) compared to those of professionals (mean = 4.9; SD 1.5) when reporting satisfaction with services. The results suggest services should take into account child's age, delays in accessing services, and active stakeholders' participation when looking to improve services.

Keywords Autism spectrum disorder · Early detection · Diagnosis · Patient satisfaction · Mental health services · Survey

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder of early onset, characterized by deficits in social communication, along with restricted and repetitive patterns of behavior, interests or activities which have significant consequences in daily life (American Psychological Association, APA 2013; World Health Organization 2018). When parents first begin to worry about their child's developmental difficulties, they must make a considerable effort to seek answers to their questions and obtain an accurate

diagnosis. Families face the challenge of adapting to the new and unexpected reality of having a child with autism in the family, reorganising family roles, finding appropriate treatment/s, and in many cases paying for specialist input (DePape and Lindsay 2015; Hock et al. 2012; Keenan et al. 2010). Several studies indicate that parents of children with ASD report higher stress levels and lower service satisfaction than do parents of children with other disabilities (Baker-Ericzén et al. 2005; Gray 2006; Griffith et al. 2010; Hayes and Watson 2013). Families with a young child with ASD report greater difficulties in accessing services, higher associated costs, and a lack of information and support during the diagnostic process (Hodgetts et al. 2015; Kogan et al. 2008; Thomas, Parish et al. 2012a; Wang et al. 2013).

These families' challenges have been associated with factors linked, not only to the child's characteristics, but also to family characteristics, sociodemographic factors and the characteristics of service delivery. With regard to sociodemographic aspects, observation has shown that individuals

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with ASD belonging to families with a high parental socioeconomic status (SES) and high parental educational level are diagnosed earlier, and that their families report greater satisfaction with the diagnostic process (Durkin et al. 2010; Goin-Kochel et al. 2006; Irvin et al. 2012; Moh and Magiati 2012; Thomas, Zahorodny et al. 2012b).

In relation to the services provided to young children with ASD, the sources of distress and dissatisfaction mentioned by parents are professionals' tardiness in addressing their initial concerns, delay in getting a diagnosis, and the lack of professional support (Altiere and von Kluge 2009; Bishop et al. 2007; Bluth et al. 2013; Crane et al. 2016; Divan et al. 2012; Moh and Magiati 2012; Osborne et al. 2008). It has also been suggested that some families' low level of satisfaction with the care they receive is related to communication difficulties between families and professionals (Liptak et al. 2006), inadequate organisation of care programmes (Chiri and Warfield 2012), and the absence or scarcity of skilled professionals specialised in ASD (Krauss et al. 2003). A very recent study (Crane et al. 2018) on the views of families, professionals and adults with autism about the diagnostic process found that delays to diagnosis of ASD and the lack of rapport between parents and professionals affected satisfaction with services. In addition, families wanted more guidance, counselling and emotional support to help them to understand the meaning and the implications of the diagnosis received, in order to be able to avoid crisis in the family and manage stress adequately (Crane et al. 2018).

Despite the difficulties expressed by families and professionals alike, it is generally accepted that, over the years, progress has been made in improving care for children with ASD (Austin et al. 2016), even though further improvements are still clearly required. In recent years, efforts to improve detection, diagnosis and early intervention services for children with ASD have paid more attention to the views of families and professionals, reflecting the belief that improvement strategies should focus on the child and his or her family (McConachie et al. 2015; Pellicano et al. 2014). The purpose is to ensure that families are more actively involved in assessment of the child's and the family's needs, and that professionals take a proactive approach to identify such needs. Families that report being actively involved in decisions and have good communication with professionals also report greater satisfaction with services, fewer gaps in services, fewer delays in accessing treatment and services, lower stress, and lower general ASD-related costs (Kuo et al. 2011; Moh and Magiati 2012; Burke and Goldman 2015). Likewise, recent studies have shown that, when professionals respond promptly to parents' concerns, delays in access to diagnostic services are reduced and overall satisfaction is increased (Zablotsky et al. 2017; Zuckerman et al. 2015).

An increasing number of researchers are taking advantage of social networks and institutional websites to distribute

surveys aimed at exploring the state of art about unmet needs and services (Gotham et al. 2015; Zhao et al. 2019). These surveys are based on large proportion of responses and they constitute a cost-effectiveness procedure for the analysis of the situation and hypothesis generation, even though they fail providing inferences free of bias. However, they are excellent tools when analysing a large and diverse population.

Although the opinions and satisfaction of families and professionals with early detection, diagnosis, and early intervention services seem to have played a fundamental role in changing policies and improving services for the ASD community, the perspectives of these two different groups have rarely been considered together. Hence, it is important to obtain detailed information about the type of services which young children with ASD receive and the views held by various European stakeholders on such services, in order to inform the decisions of policy makers -at both a national and European level- affecting the financing of services and training of families and professionals.

To this end, we used the Autism Spectrum Disorder in the European Union (ASDEU 2015–2018) network to conduct a multinational study aimed at assessing and collecting the opinions and attitudes of the autism community (families and professionals) concerning early detection, diagnosis and intervention services for children with ASD under 9 years of age in 14 European countries. More specifically, our objectives with regard to early detection, diagnosis and intervention services were: (a) to identify the types of services received by children with ASD in Europe; (b) to examine families' and professionals' degree of satisfaction with services across Europe; (c) to explore variations in age at detection, diagnosis and intervention and delays in accessing services, as reported by parents and professionals; and lastly (d) to identify the variables that predict service satisfaction in both groups.

Methods

Survey Development

The development of the surveys was carried out in three steps. The first was a focus group activity aimed at obtaining initial direct information about the perceptions and ideas of people normally involved in the processes of detection, diagnosis and early intervention of children with ASD. This information helped us to delimit the content and topics of interest that we were going to include in the surveys. The second step focused on the development of the items and the structure of the questionnaires. The last step consisted of a controlled distribution of the survey (pilot study) to a group of families and professionals with the purpose of identifying

difficulties in understanding the items and evaluating the functioning of the survey.

Focus Groups

In this first step, twenty focus-group sessions were conducted across the ASDEU network. Taking into consideration the purpose of the study, we distributed the focus groups in relation to two thematic areas: (a) early detection and diagnosis; and (b) early intervention. Each of the 10 participating European countries conducted two focus group sessions addressing each of these two topics. The countries involved were Bulgaria; Denmark; Finland; France; Iceland; Italy; Poland; Portugal; Romania; and Spain. The size of the groups ranged from 5 to 11 participants, with a total of 225 participants in all (146 (64%) professionals and 79 (36%) familiars). Each focus group was led by a facilitator and one other researcher who was present as an assistant. The topics discussed were the age of access to services, delays in receiving necessary services and/or treatments and their causes, satisfaction with the care and treatments received, knowledge about autism that participants attribute to professionals, the limitations of the services (economic, in material resources, trained personnel), the participation of the family in the diagnosis process and during the treatment activities, the best practices known to the participants, the level of training in diagnosis and/or treatment that professionals have and that provided to families to meet the needs of children, coordination between services and general procedures that participants know for early detection, diagnosis and early intervention in each country.

Survey Content and Structure

Participants of focus groups were not directly involved in the creation of the surveys. The authors of this article analysed the transcripts obtained from the focus group discussions, extracting and grouping into categories and ordering the ideas, perceptions, concerns, and interests expressed by the participants. This set of categories served to elaborate the items of the questionnaires and to organize the surveys differentiating questions directed to families and questions directed to professionals. Following this procedure, two different surveys were drawn up to facilitate collection of data from the two respondent groups, namely, parents or families and professionals who were directly related to a child with ASD, (Appendixes 1 and 2 for Final Survey English Version).

Section one collected basic information about respondents' gender, age, country and city of residence. In addition, family members were asked about their relationship to the child, academic attainment, number of people living permanently in the household, and the gender, age, diagnosis

and verbal ability of the child. Diagnostic categories were defined according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases for Mortality and Morbidity Statistics (ICD) classifications (APA 2013; WHO 2018). Professionals, on the other hand, were asked about their main job and their experience in working with children with autism.

Sections two to four contained questions on early detection, diagnosis and early intervention respectively. Both the family member and professional surveys included a brief introductory explanation of the type of questions that the respondent would have to answer. Professionals were asked whether they were directly involved in any programme dealing with early detection, diagnosis or early intervention. Those who responded negatively to these questions were asked to provide contact details of someone involved in such programs, and then directed to the end of the survey. These respondents were not included in the final sample. Of the 35 participants nominated in this way, 28 participated in the survey. The questions were intended to elicit specific data on the processes of detection, diagnosis and beginning treatment, from the moment when families or professionals first began to worry until the time when the specialist treatment began. Respondents were thus asked about the age of the child when concerns first arose (detection), age at diagnosis and age when treatment or intervention started, as well as any delays in access to services, types of professional involved in the different processes, type of diagnosis, degree of family involvement at each stage, type of intervention, and the like. Therefore, the survey included specific questions about satisfaction with detection, diagnosis and intervention (See Appendixes 1, 2).

The principal response categories were: (i) age of the child at the time of accessing to detection, diagnosis and intervention services (families: list from 0 to 9 years; professionals: based on different ranges). The answers were stratified as 0–18, 18–24, 24–36, and > 36 months at detection; 0–18, 18–32, 32–46, 46–60, and > 60 months at diagnosis and intervention. (ii) Delays in access to services ranging between 0 and 3 months, 3–6 months, > 6 months. (iii) Assessment the satisfaction with services on a scale of 1 to 7 (1: extremely inadequate; 2: moderately inadequate; 3: slightly inadequate; 4: neither adequate nor inadequate; 5: slightly adequate; 6: moderately adequate; 7: extremely adequate). The different answer choices for all aforementioned questions were then stratified and recoded into three new categories, namely, negative (from 1 to 3), neutral (4) and positive (from 5 to 7). (iv) The level of participation in the intervention sessions. Parent participation were stratified into two categories, namely, active participation (very actively and actively participation responses) and occasional/no participation (occasional participation and I don't participate responses).

Survey Testing

After translation and adaptation by researchers from the respective project countries, 14 country-specific versions of the survey were produced. This process included the use of official translations of some questions (e.g., intervention programs, manuals, etc.) where available in each country. The translations were uploaded to the Qualtrics web platform (<https://www.qualtrics.com>), altrics web platform (<https://www.qualtrics.com>).

Before the surveys were publicly launched, they were piloted in three countries (Spain, Denmark and Iceland) with the support from twelve parents from six family' organisations, five professionals from the ASDEU project network and three professionals not directly related to the project. Parents 12 (60%) and professionals 8 (40%) were asked to give their opinion on the content, format and accessibility of the surveys. All pilot respondents reported that the survey was accessible and that the questions were clear and comprehensible, indicating no need to further adapting wording or length of questions. Participants completed the survey in 15–20 min. The Flesch reading Ease was 60.8 and the Flesch-Kincaid Grade Level was 8 (word office tool). These scores were within the standards for a document to be accessible and easy to read for the population.

Recruitment Procedure

The survey was made available online and distributed by researchers affiliated to the ASDEU project website in the 14 participating countries. The main goal was to secure the largest possible sample from the countries that participated in the project, so as to obtain a global analysis that would be useful for the management of new hypotheses. Clinical practitioners as well as parents' and professionals' organisations promoted the survey through their own networks. Professionals were asked to distribute the survey to family members of children under 9 years old receiving a treatment for ASD and give them guidance on how to respond. Invitations to participate in the survey were also sent to websites visited frequently by the ASD community, i.e., service providers, private and public associations, Facebook groups, Twitter, bulletins, etc. In addition, links to the survey were provided in the online newsletter of the ASDEU project (<http://asdeu.eu/newsletter/>). Special education Schools, rehabilitation centres working with children with neurodevelopmental problems, psychiatry services for child and adolescent, home guidance centres and residential centres for children with ASD participated in the surveys and disseminated them through the families. Finally, a global sample was obtained from a total of 24 countries. The surveys were available online, so that any professional or family member of a child

with autism could answer them, regardless of the country from which they came.

Ethical Approval

Ethical approval was given by the Ethics Committee of the University of Salamanca, Spain (201700008785). Respondents accessed the survey from this server. The same survey was conducted in all countries. There was a global survey in several languages, which participants accessed and consented to answer: prior to starting, all respondents were required to read the information about the survey and give their informed consent electronically.

Data Analysis

As the survey was administered electronically, the data were downloaded for further analysis, which was conducted in four distinct phases.

Comprehensive descriptive analyses of the two respondent groups (families and professionals) were performed.

Multinomial regression analyses were conducted to compare parents' and professionals' reports with respect to the following four different dependent variables: (i) age of access to services, to examine the likelihood of the child being detected, diagnosed and beginning the intervention earlier; (ii) delay in access to services, to ascertain who, parents or professionals, reported the longest waiting times; (iii) satisfaction with services, to examine the likelihood of positive versus negative satisfaction with detection, diagnosis and intervention; and (iv) lastly, whether parent participation was associated with intervention satisfaction.

Finally, to investigate the different items that predict (independent variables) the positive satisfaction of the early detection, diagnosis, and intervention services (dependent variables), multinomial logistic regressions models were made with the age of access to services and delays in accessing these services.

Results

Sample Characteristics

Although a total of 3693 people initiated the survey, only 2032 respondents met the inclusion criteria (Tables 1 and 2). The reasons for exclusion of the remaining 1661 respondents were: (1) failure to complete an adequate percentage (70%) of survey sections two and three; (2) not having a child with ASD in the family; (3) not working for institutions with ASD among their services, respectively; (4) not a European resident (European area). Countries with fewer than

Table 1 Sample size by respondents' countries

	Family members <i>n</i> = 1237	Professionals <i>n</i> = 795	Total <i>N</i> = 2032 (%)	
Austria	23	12	35	1.7
Belgium	159	40	199	9.7
Denmark	94	96	190	9.4
Finland	52	200	252	12.4
France	105	140	245	12.0
Great Britain	19	1	20	1.0
Iceland	50	45	95	4.7
Ireland	79	15	94	4.6
Italy	86	30	117	5.7
Poland	222	79	301	14.8
Portugal	25	10	35	1.8
Romania	28	–	28	1.4
Spain	278	116	393	19.4
The Netherlands	6	4	10	0.5
Other	11	7	18	0.8

Countries in the "Other" category: Norway, Switzerland, Germany, Malta, Cyprus, Slovenia, Hungary, Croatia, Russia, Macedonia

five respondents were included in the sample but country-specific statistics were not reported.

The family group was the larger of the two respondent groups, with 1237 respondents (60.9% of all respondents). The majority of respondents in the family group were parents (81.3% mothers), with the most frequent educational level being a first degree or higher (64%). The average age of children with ASD in such families at the date of completing the survey was 76.7 (*SD* 31.0) months, and most of these children were male (82.7%). A total of 795 professionals answered the survey (39.1% of the whole sample), most of whom (90.3%) were women. The largest group were those working in mental health services (psychologists, psychiatrists or mental health therapists), followed by those working in other health services (general practitioners, paediatricians or nurses) and teachers working in the educational system. About two-thirds of professionals (64.2%) reported that they had more than 5 years' experience in that job.

Table 2 Sample characteristics and information about services by respondent type

	Family members, <i>n</i> = 1237	Professionals, <i>n</i> = 795
Age of respondents in years, mean (SD)	50.8 (7.1)	45.8 (11.5)
Gender (% male)	14.6%	9.7
Relationship to child (father: mother: other ^a)	14.2%: 81.3%: 4.5%	NA
Educational level—first degree or higher	64.0%	NA
Child's age at time of survey, mean (SD)	76.7 (31.0)	NA
Child's gender (% male)	82.7%	NA
Profession—health: mental health: education	NA	34%: 39%: 17%
Professional experience—1–3 years: 3–5 years: > 5 years	NA	20%: 15%: 64%
Person who first raised concerns—caregiver: professional	70%: 30%	NA
Source of concern about services—professional's concern: survey	96%: 3%	NA
Professional involved in detection—health: mental health: education	21%: 28%: 11%	22%: 25%: 13%
Professional involved in diagnosis—health: mental health	48%: 77%	63%: 90%
Diagnostic classification used: DSM: ICD	–	23%: 26%
Information received in diagnosis—medical: educational: social: none	31%: 45%: 29%: 20%	69%: 84%: 81%: 4%
Intervention information—results: programme type: cost: participation: none	NA	71%: 66%: 19%: 13%
Time of sessions, mean (SD)	0.81 (0.22)	1.90 (1.22)
Session format—group: individual	31%: 89%	40%: 75%
Parental participation—active: occasional: none	40%: 29%: 30%	73%: 22%: 4%
Distance to early intervention service (km), mean (SD)	12.6 (14.8)	NA
Travel time to early intervention service (minutes), mean (SD)	21.8 (15.1)	NA
Intervention programme: specific to ASD (e.g., Applied Behaviour Analysis): health: parental training	24%: 49%: 47%	NA
Age of access to detection services in months, mean (SD)	18.3 (13.4)	NA
Age of access to diagnostic services in months, mean (SD)	36.4 (17.7)	NA
Age of access to intervention services in months, mean (SD)	42.2 (15.4)	NA

^aGrandparents, siblings

All percentages exclude missing values

Early Detection, Diagnosis and Intervention Services

The majority of family respondents (70%) indicated that the first person to suggest that something was wrong with the child's development was a family member (Table 2). In general, family respondents said that they relied on the professionals' experience of typical development to recognise warning signs; only 3.1% said that they had noticed problems after responding to a specific ASD screening survey [e.g., M-CHAT-R (Robins et al. 2014) or Q-CHAT (Allison et al. 2008)]. Both respondent groups reported that the professionals most frequently involved in the detection and diagnostic processes were those working in mental health services. Professionals reported that they informed families about the child's specific needs, highlighting the educational needs. Caregivers also reported this, however, noteworthy 20% of the families reported that they did not receive any information (e.g., medical or educational needs) at the time of the child's diagnosis. The majority of professionals reported using the DSM (23%) or ICD (26%) diagnostic classification at their centers.

Most family respondents indicated that they were not involved (40%) or only occasionally involved (30%) in the intervention process, whereas 70% of professional respondents reported that parents participated actively in interventions. Only 13.1% of professionals reported that they had not provided parents with information about intervention programs when their child started treatment. Family respondents indicated that the most commonly recommended interventions were speech therapy, physiotherapy and parental training sessions. Specific intervention programs to ASD people were available for 24% of the families respondents. The number of sessions that children with ASD receive according to their families was lower than the number of sessions reported by professionals. Both groups reported that the majority of sessions that children with ASD received were individual sessions. The distance and time to reach the intervention services varied greatly, ranged from 1 to 100 kilometres and 1 to 60 min.

Age at Detection, Diagnosis and Intervention, and Delay in Access to Services

The main objective of this comparison was to ascertain which type of participant reported lower access ages and whether these differences were statistically significant ($p < 0.05$). Additionally, the analysis was conducted to examine the likelihood of the child having fewer delays in access to detection, diagnostic and intervention services. According to family respondents, the average age at which concerns were first raised about the child who was later diagnosed with ASD, was 18.3 (SD 13.4) months. The average age at diagnosis was 36.4 (SD 17.7) months, with most diagnoses

occurring between 32 and 46 months according to both families and professionals. Professionals reported that the age of most detected cases ranged from 24 to 36 months. Average age of starting an early-intervention programme reported by families was 42.2 (SD 15.4) months (Table 2).

Detection of symptoms appearing before the age of 18 months were more likely reported by family respondents compared to professionals. Also, families were more likely than professionals to report a delay detection over 6 months (Table 3). Again, most families reported a delay in the access to diagnostic services over 6 months, compared

Table 3 Age at detection, diagnosis and intervention and delays in access to services: group comparisons

	% Family members ($n=1223$)	% Professionals ($n=786$)	Family members vs. professionals OR (95% CI)
Child's age at detection			
0–18 months*	41.7	13.1	
18–24 months	7.4	30.8	0.11 (0.07–0.17)
24–36 months	31	42.1	0.31 (0.21–0.45)
> 36 months	19.9	14	0.66 (0.41–1.09)
Delay in access to detection services			
0–3 months*	21.6	23.3	
3–6 months	29.4	41.1	0.89 (0.62–1.28)
> 6 months	50	35.6	2.90 (2.11–3.98)
Child's age at diagnosis			
0–18 months*	3.1	2.1	
18–32 months	26.8	30.5	0.44 (0.27–0.71)
32–46 months	31.9	42.4	0.39 (0.25–0.62)
46–60 months	17.6	14	0.66 (0.38–1.14)
> 60 months	20.6	11	1.48 (0.46–3.54)
Delay in access to diagnostic services			
0–3 months*	9.8	29.4	
3–6 months	22.2	41.2	0.23 (0.17–0.33)
> 6 months	68	29.4	6.93 (4.75–10.12)
Child's age at start of intervention			
0–18 months*	5.1	7.7	
18–32 months	42.0	52.0	0.98 (0.96–1.02)
32–46 months	34.5	31.7	1.00 (0.98–1.02)
46–60 months	14.2	6.1	1.03 (1.01–1.05)
> 60 months	4.2	2.5	1.01 (0.99–1.03)
Delay in access to intervention			
0–3 months*	62.6**	56.5	
3–6 months	22.9	18.7	1.11 (0.73–0.81)
> 6 months	14.8	24.7	0.54 (0.36–0.81)

The table reports odds ratios (ORs) and the corresponding 95% confidence intervals (CIs), χ^2 and Nagelkerke's R^2 . Predictors significant at $p < 0.05$ are indicated in bold

*Reference category

**14.8% of the 0- to 3-month group received an intervention before diagnosis

to 3–6 months reported by professionals. However, it was professionals more often than families who reported a longer delay -of over 6 months- in access to intervention services.

Satisfaction with Services in Relation to Respondent Characteristics

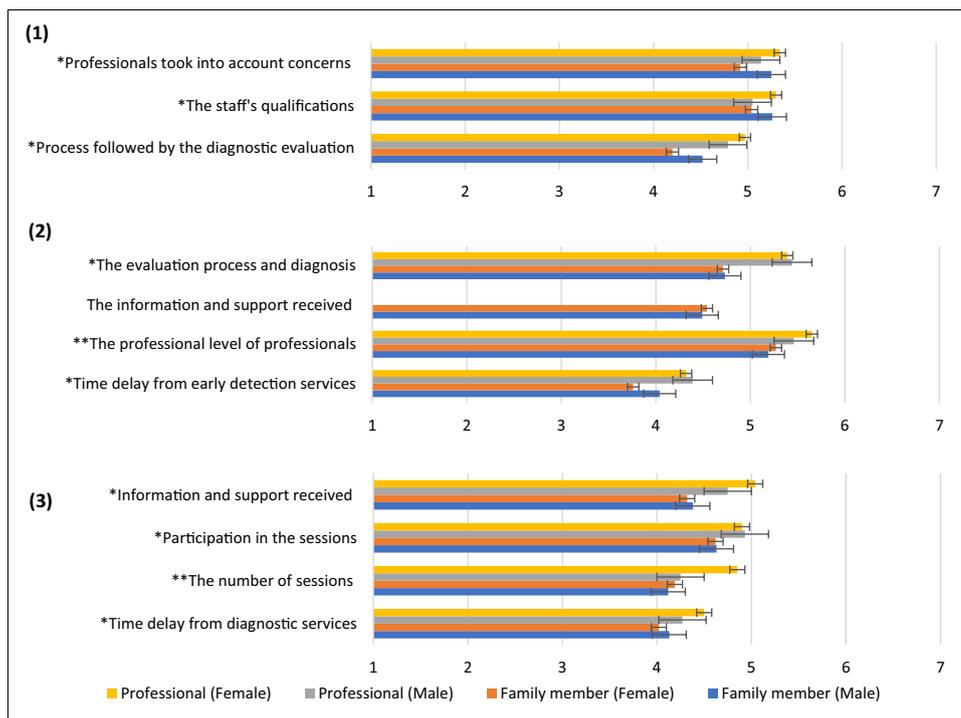
Interaction terms in the models were used to explore differences between families and professionals, taking into account respondents' sex where appropriate. To this end, separate analyses were performed for professionals and families (familial male vs. familial female; professional male vs. professional female). The sample size for these analyses was 2032. Figure 1 illustrates the mean rankings (from 1: extremely inadequate, to 7: extremely adequate) provided by each male and female respondent in each respondent group. Rankings indicate significant differences between respondents by group (families/professionals) and sex. Families were more likely to express less positive satisfaction (scale from 4 to 7, see Fig. 1) than professionals for all items evaluated (Table 4). Regarding detection, we found greater differences between families and professionals in the evaluation of the general process, as well as in the degree to which the professionals took into account the family's concerns. Regarding diagnostics, the greatest differences were found in the general evaluation of the process, in addition to the

professional level of the team involved. Differences between families and professionals about the information and support received, as well as the number of sessions, in the evaluation of the intervention were also found, which previously noticed in the description of the services, reported by families and professionals (See Table 2).

No sex-related differences were observed except in the case of females in the professional group, who had a more positive opinion than did their male counterparts about specific factors in the diagnosis and intervention programmes. Female professionals were more likely to express more positive satisfaction than male professionals for the items "The staff's qualifications" (Detection) and "The number of sessions" (Intervention) (Fig. 1; Table 4).

Comparisons across participants regarding to their participation in the intervention sessions and the assessment of the service were conducted. The main goal of this analysis was to ascertain whether active participation by parents resulted in more positive satisfaction with services. The different answer choices for these questions were collapsed to examine the likelihood of positive versus negative satisfaction with parent participation (active participation vs. occasional/no participation). Families who were actively involved were more likely to express more positive satisfaction with the intervention process than were those families who did not participate or only participated occasionally (Table 4). This

Fig. 1 Average opinion of services by family and professional respondents by sex. (1) Early detection process, (2) early diagnostic process, (3) early intervention process. Scale: from 1 (extremely inadequate) to 7 (extremely adequate), collapsed and transformed into the following categories: negative (from 1 to 3), neutral (4) and positive (from 5 to 7). *Difference between family and professional respondents; $p < 0.05$. **Sex difference within a respondent group; $p < 0.05$



(1) early detection process, (2) early diagnostic process, (3) early intervention process. Scale: from 1 (extremely inadequate) to 7 (extremely adequate), collapsed and transformed into the following categories: negative (from 1 to 3), neutral (4) and positive (from 5 to 7)

* Difference between family and professional respondents; $p < 0.05$

** Sex difference within a respondent group; $p < 0.05$

Table 4 Comparison of satisfaction among respondents according to sex and parents' participation in the intervention

	Family members vs. Professionals ^b	Male family member vs. Female family member ^b	Male professional vs. Female professional ^b	Active participation vs. occasional/no participation ^b
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Detection				
Process followed by diagnostic evaluation ^a	0.40 (0.32–0.49)	1.41 (0.99–2.00)	0.81 (0.45–1.45)	–
Staff qualifications ^a	0.62 (0.49–0.79)	1.17 (0.79–1.74)	0.66 (0.36–1.20)	–
Professionals took into account family's concerns ^a	0.45 (0.35–0.57)	1.44 (0.96–2.16)	0.69 (0.36–1.32)	–
Diagnosis				
Delay between detection and diagnostic services ^a	0.60 (0.50–0.74)	1.23 (0.89–1.71)	1.18 (0.69–2.01)	–
The professional level of professionals ^a	0.45 (0.34–0.60)	0.98 (0.65–1.46)	0.43 (0.22–0.82)	–
Information and support received ^a	–	0.89 (0.64–1.26)	–	–
The evaluation process and diagnosis ^a	0.37 (0.28–0.47)	0.85 (0.60–1.20)	0.72 (0.37–1.41)	–
Intervention				
Information and support received ^a	0.41 (0.31–0.53)	1.01 (0.69–1.49)	0.58 (0.18–1.37)	1.85 (1.28–2.66)
Participation in sessions ^a	0.69 (0.53–0.91)	1.14 (0.73–1.76)	0.81 (0.42–1.56)	1.60 (1.06–2.43)
Number of sessions ^a	0.47 (0.37–0.60)	0.91 (0.63–1.33)	0.46 (0.25–0.83)	1.52 (1.06–2.17)
Delay between diagnosis and start of intervention ^a	0.71 (0.51–0.95)	0.96 (0.66–1.39)	0.61 (0.20–1.12)	1.46 (1.03–2.09)

The table reports odds ratios (ORs) and the corresponding 95% confidence intervals (CIs). Comparisons significant at $p < 0.05$ are indicated in bold

(–) Not applicable. Not asked or not possible to calculate

^aSatisfaction ratings were classified into 3 groups: 0 = negative (reference category), 1 = neutral, and 2 = positive

^bReference group in the multinomial logistic regression

effect applied to all the aspects of intervention that were evaluated, highlighting the information and support received over the rest of the items evaluated.

Relationships Between Age at Detection, Diagnosis and Intervention, Delay in Access to Services and Satisfaction with Services

Multinomial logistic regressions models were fitted with the following independent variables: (1) age of detection (0–18 months), diagnosis (0–24 months), and intervention (0–36 months); and, (2) delays in accessing such services (> 6 months). Separate analyses of the total sample were performed for each group of participants. Families of children who reported to have been detected at an early age and have had less delay in access to this service were more likely to express higher family positive satisfaction with detection services (scale from 4 to 7, see also Fig. 1). Table 5 shows the odds ratios (ORs) for each predictor vis-à-vis each outcome measure of satisfaction (See Appendix 3 supplementary material all items evaluated separately). By reducing the age of detection, the perception of detection services would be more positive in all items for families. In addition, families who reported delays in access an early detection service

of more than 6 months score the process worse. On the other hand, professionals who reported early child's age of detection were more likely to express higher positive satisfaction in any of the items related to the assessment of detection services (Table 5).

The results for diagnostic services follow a similar pattern to screening services for families only. Families who reported less delay in access to detection and diagnostic services were more likely to express higher satisfaction. On the contrary, professionals who reported early child's age of diagnosis and less delays in access to this service were not more likely to express higher satisfaction with diagnostic services (Table 5).

Finally, the results indicated that the same families of children who reported shorter delays in access to detection, diagnosis and early-intervention programmes were more likely to express higher family positive satisfaction of intervention services. Therefore, by reducing the delay in access to detection, diagnosis and intervention, the assessment of intervention services would be more positive. On the other hand, professionals who reported early child's age of intervention and less delays in access to this service were not more likely to express higher positive satisfaction in any of the related items. (See Table 5 and Appendix 3).

Table 5 Predictors of positive satisfaction

	Detection OR (95% CI)	Diagnosis OR (95% CI)	Intervention OR (95% CI)
Family members			
Child's age at detection (0–18 months)	2.05 (1.46–2.90)	1.50 (1.04–2.17)	1.40 (0.97–2.01)
Delay in access to detection (> 6 months)	0.22 (0.15–0.33)	0.18 (0.11–0.29)	0.42 (0.29–0.61)
Child's age at diagnosis (0–24 months)	–	2.41 (1.18–4.93)	2.14 (1.18–3.88)
Delay in access to diagnosis (> 6 months)	–	0.29 (0.16–0.56)	0.56 (0.34–0.92)
Child's age at intervention (0–36 months)	–	–	2.08 (1.23–3.86)
Delay in access to intervention (> 6 months)	–	–	0.56 (0.36–0.89)
Professionals			
Child's age at detection (0–18 months)	0.55 (0.12–2.58)	0.80 (0.09–8.02)	2.23 (0.35–16.7)
Delay in access to detection (> 6 months)	0.25 (0.07–0.68)	0.68 (0.14–5.79)	0.44 (0.11–1.12)
Child's age at diagnosis (0–24 months)	–	0.55 (0.07–5.60)	0.71 (0.21–3.29)
Delay in access to diagnosis (> 6 months)	–	0.74 (0.11–5.98)	0.89 (0.35–2.42)
Child's age at intervention (0–36 months)	–	–	2.32 (0.65–5.59)
Delay in access to intervention (> 6 months)	–	–	0.53 (0.19–0.86)

Discussion

The aim of this study was to analyse the characteristics of detection, diagnosis and intervention services received by children with ASD, and to compare and contrast the overall satisfaction reported by 1223 families and 760 professionals, in order to provide an evidence based framework for clinicians, decision-makers and researchers to consider, and so enable them to incorporate the views of these groups into their activities. Rather than seeking to be representative of the entire EU, this study sought instead to obtain a representative sample of most of the countries that participated in the ASDEU project (14), so as to make a global analysis that would be useful for the management of new hypotheses and changes. Since it was a free-access survey, it was not possible to control for the fact that in some countries the response of the participants was lower than expected. Although the unequal size of the number of participants in the respective countries renders it impossible to draw conclusions for a particular country, this is not so for all of them. Similarly, the fact that it was an open-access survey meant that some participants who were in the European region but outside the EU, responded to the survey. These participants were taken into account in the global analyses.

Overall satisfaction of participants was positive (> 4 on the scale) for all early detection, diagnosis and intervention items evaluated (Fig. 1). Survey participants tend to be more engaged in the process than non-respondents, and more likely to have had positive experiences with services, as well as more positive attitudes of the participants (Keusch 2015). Although overall satisfaction was positive, professionals were more satisfied than family members (Table 3). These differences could be due to the fact that families have to deal with the process not only of gaining recognition and

acceptance of the fact that there is something wrong with their child's development, but also of waiting for services, as well as the sheer amount of services and medical visits that children with ASD need, all of which results in higher levels of stress (Burke and Goldman 2015; Summers et al. 2005). In addition, differences could be due to the fact that families respond based on their personal experiences, while the professionals respond based on the experiences across all of the parents they attend. Whereas providers might recognize that delays in the diagnosis or the onset of services is not optimal, they do not experience the frustration experienced by families, accumulated each month. As a consequence, these differences should be interpreted carefully in light of the great disparity between responders' respective experience of the process. For instance, significant differences were found in satisfaction with the number of intervention sessions (Table 4). Based on their experience, parents reported receiving less than half the time in intervention sessions that those reported by professionals, which would show how the personal experiences lived in the services could affect to satisfaction. Dissatisfaction with the information provided by practitioners, the support received and the delays in access to services observed in this study is consistent with the findings of previous studies (Dymond et al. 2007; Hodgetts et al. 2015; Liptak et al. 2006; Ngui and Flores 2006; Rogers et al. 2016). However, no previous studies have shown differences between family members and professionals in terms of satisfaction with detection, diagnosis and intervention services. Future studies should therefore focus on the reasons for these differences.

The ages of detection, diagnosis and access to intervention reported by family members are markedly lower than those reported in some previous studies (Baio 2018; Oswald et al. 2017) but similar to those reported in others (Adelman

and Kubiszyn 2017; Daniels et al. 2017; McIntyre and Zemantic 2017; Moh and Magiati 2012). It is possible that the variation in families' reports of age at first access to services for children with ASD simply reflects differences in socio-economic status, since it has been observed that families with greater socio-economic resources enjoy better access to services and specialists. Families with low socio-economic resources tend to report higher ages of access to services (Kalkbrenner et al. 2011; Liptak et al. 2008). Another possible explanation lies in differences in parent awareness of their child's early difficulties (Daniels and Mandell 2014; Sacrey et al. 2015; Zablotzky et al. 2017; Zuckerman et al. 2015). In this study, 70% of families reported having had some concerns about the development of the child who was subsequently diagnosed with ASD, something that may have reduced the age of detection and diagnosis, and thus speeded up access to an intervention programme. Families reported that the average delay between detection and diagnosis (18.1 months) was much longer than between diagnosis and treatment (5.8 months), and 14.8% of families reported that their child had started an intervention programme (private or public) before receiving a formal diagnosis. Another possible explanation could be the fact that in this type of surveys the participants were more aware and had greater resources, both personal and material. Because the recruitment process for the survey was carried out in parent associations, as well as in other ASD specific services, participants may have had access to resources such as diagnosis or intervention, which would significantly reduce delays to these services. Parents who are more engaged are more likely to be concerned earlier and to have experienced relatively longer delays in accessing services such as diagnosis. Future studies should investigate whether satisfaction with services is more closely linked to the length of delays in access or to the age at which the child obtains access to services.

Differences between families and professionals could be related to their differing experiences. In their recent experience, professionals may have conceivably dealt with cases where diagnosis was made quite early and delays in access to services were short, with the result that these recent positive experiences may have influenced their estimation of the promptness with which services respond to parents' concerns. However, the fact that families reported tardier and slower responses than did professionals would suggest that service lags exist and there is a need to provide professional staff with technical and human resources (training programmes and tools) which will speed up the detection and diagnostic processes and reduce delays in access to such services.

Families who had early access to services and experienced fewer delays tended to rate services more positively. These results are consistent with studies such as those by McKenzie et al. (2015) and Kuo et al. (2011), where parents

who reported the greatest satisfaction with the information and support received were those whose child had been younger at the time of diagnosis. Most of the families that participated in the study reported that, after becoming concerned about their child and communicating their concerns to a paediatrician, they had to wait, first for a diagnosis of ASD from a specialist service and then for an intervention programme. In contrast, professionals' evaluations were more positive and more uniform than those of families, and they reported that waiting times were shorter and children younger when they gained access to services. This could be explained due to the fact that family members must complete the entire process, from detection to intervention, while professionals may belong to one of these services. Therefore, the experiences of family members, who have to go from one service to another will tend to be more negative.

An important finding related to detection is that very few families reported participation in ASD-specific screening programs (3.1%). These results are in line with previous studies on the use of ASD-specific programs in the USA (Adelman and Kubiszyn 2017) and Europe (García-Primo et al. 2014). However, 70% of families reported having expressed concerns to different professionals, which would imply the start of a development screening program. Therefore, detection was primarily based on the experience and knowledge of the professional. Use of an effective and efficient screening tool would allow professionals to detect potential ASD cases at an earlier age and refer them to diagnostic services earlier, thus reducing the delay between detection and diagnosis, which can be as long as 18 months, according to families. Reducing the delay in diagnosis would enable children to begin intervention programmes earlier. If intervention occurs early, when neuronal plasticity is much greater, long-term positive results can be achieved (Crais and Watson 2014a). It has been widely reported by paediatricians that there are many barriers to detection of ASD and the use of population screening programmes (Crais et al. 2014b), and there have been warnings about the lack of training to enable early detection of a disorder which is diagnosed frequently every year.

This study shows that active parental involvement increases family satisfaction with services, a finding consistent with other studies which show that parental involvement is fundamental to satisfaction with intervention programmes (McIntyre and Zemantic 2017; Stadnick et al. 2013). In recent years, active involvement has also been shown, not only to increase service satisfaction, but also to improve intervention outcomes by, for instance, increasing progress in skill acquisition (Ingersoll and Wainer 2013; Kasari et al. 2015; Pickles et al. 2016). In addition, involving parents reduces the costs of intervention programmes by decreasing the number of hours with professionals and increasing skill development in natural contexts (Ingersoll et al. 2017;

Pickles et al. 2016). All these factors mean that parental involvement in interventions reduces the economic burden on the family, health-care system and society, along with the stress associated with having a child with ASD (Kasari et al. 2015).

Limitations

One of the study limitations is that surveys targeted at EU-sized populations can only estimate the thrust of the analysis and establish hypotheses, but such hypotheses can never be considered definitive. One cannot ascertain the total number of family members with ASD children or professionals who work with this group in Europe. In terms of their external validity (generalization), these results should therefore be interpreted with caution. This study represents the first approach to comparing parents' and professionals' perceptions of the services made available to children with ASD. Accordingly, it falls to future studies to compare these same groups using larger sample sizes.

Another limitation is that our family sample was more highly educated (most respondents had a university degree or higher) and not as diverse as that of other studies (Mandell and Salzer 2007; Thomas, Zahorodny et al. 2012b). Even so, our study sample group was similar to many other studies based on surveys of families of children with ASD and professionals (Casagrande and Ingersoll 2017; Liptak et al. 2008; Weiss et al. 2012). In addition, participation in the study was limited to people with Internet access, a factor that may have excluded some potential low-income respondents without good access to the Internet. These potential sources of selection bias may have rendered the sample unrepresentative of the general community (Salomone et al. 2015). Although online surveys are commonly used and the limitations associated with them are well known, it is possible that our results cannot be generalised to populations with lower socio-economic levels. Sample size differed from country to country, and consequently countries with large samples may not be representative of all the countries that were included within a given category. An additional limitation of our sample was that we did not have parental and professional ratings for the same individual. Future research should therefore compare the views of families and professionals about the *same* children with ASD, in order to have a more accurate picture of the differences found in this study.

Although survey dissemination was the same in all countries, parents' organizations, special education schools, centers specializing in ASD, etc., were not identical and, in addition, have different policies. The surveys were distributed to national associations and centers in each country, which then disseminated them to local associations and centers. It is impossible to ascertain the number of associations or centers that participated in the study, or the number of participants

belonging to each association or centre. It follows, therefore, that the number of participants invited by their associations or centers to complete the survey may not be the same in all countries, thereby increasing the variability of the results. Another source of variability was the type of participants that participated in the surveys. Because they were distributed mainly in services for ASD people, it is likely that highly engaged families with knowledge of ASD, as well as professionals with a high degree of experience have been the largest group of surveys participants (Table 2). Satisfaction with processes and services is usually assessed through surveys. These are so-called "self-selection" surveys (Bethlehem 2010) which are not based on probabilistic sampling. The survey is simply uploaded to the website. The respondents are those who have access to the Internet and visit the website. In our case is because they have some interest in relation to autism and decide to participate in the survey. Therefore, the participants are usually parents and professionals who are committed in some way to autism, but also with a higher level of education, and with more economic resources relative to the general population (Bethlehem 2010; Infante-Rivard and Cusson 2018). Assuming this reality, the results of self-selection web surveys can be considered representative when there are a large number of respondents, or as a result of using advanced adjustment weighting procedures in the methods of analysis (Bethlehem 2010). Future studies should compare these results with those that can be obtained by surveying parents (or family members) less involved in services and professionals with less specific ASD experience.

An additional limitation as regards respondents' characteristics is the role of the professional. This respondent characteristic was not taken into account in analyzing responses. For instance, someone in education may have a poorly informed opinion of the importance of using an ASD-detection screening tool. Accordingly, future studies should analyze the point of view of different professional profiles to ascertain whether there are differences in service satisfaction.

Another potential sample limitation is that, since the recruitment system was online and anonymous, we were unable to ascertain why some potential respondents decided not to participate. A total of 1661 people started but did not complete the survey, without it being possible to establish why they failed to complete it once they had begun (e.g., due to connection or computer problems, lack of time, distractions, etc.). It is however reasonable to assume that those who decided to complete the survey were the most committed and competent respondents, and that, by extension, may thus not be representative of the autism community as a whole (Fletcher-Watson et al. 2017).

Moreover, our data were mostly derived from responses to closed questions, which compel the respondent to select

from a fixed, restricted set of answers. Use of this question format was necessary for several reasons, such as the international nature of the survey, and the accompanying lack of translation resources to translate respondents' answers to open-ended questions. Ultimately it was a compromise, whereby the restriction on response options enabled us to collect data from a larger sample of the autism community.

Lastly, another factor affecting the range and access to services for children with ASD is location (rural, urban etc.). The location of the nuclear family has a significant impact on the number of services and professionals available (Murphy and Ruble 2012). Family and professional survey participants reported residing in urban areas. Future research should study these relationships in a more representative sample, so as to be able to provide the best recommendations, taking into account the particular characteristics of each family and the points of view of the professionals concerned.

Conclusions

Our results indicate that, though families and professionals in the autism community are broadly satisfied with services and that children's ages were lower and delays in access to services were shorter than in other studies, differences were nevertheless found between these two groups. In particular, families of children with ASD reported lower overall satisfaction with and higher child ages and longer delays in access to services than did professionals who routinely work with children with ASD. Notwithstanding this, the results suggest that, in both families and professionals, greater satisfaction with services is associated with low ages of detection and diagnosis, as this enables intervention to begin sooner. The clearest message from this study is that it is parents who are still crucial for the detection of the first ASD signs. Families are telling us that there is a need of collaborative, inclusive and self-critical professionals, and that they should be involved in every aspect of care for their child. Service policies and future research should focus on reducing delays in access to services, through, say, the implementation of early ASD-specific detection programmes, in order to increase families' satisfaction with services and thereby possibly reduce their stress and improve their wellbeing.

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Author Contributions ABM, RCB, MMM and MP designed the study and wrote the manuscript; ABM, MP and RCB carried out the statistical analyses and interpreted the results; CFA and PGP collaborated in writing the manuscript. ABM, RCB, MMM, CJF and MP designed the surveys and MRS, AB, RL, HB, SVP, DS, CW, SC, AN, FM, MLS, IM,

AY, ES, SLJ, MEB, AV, CR, BR, QG, SB, LP, JXK ODK, RK, EP and TS translated the surveys into their native languages and disseminated them in their respective countries. All authors have read and approved the final manuscript.

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Data Availability A copy of the surveys can be seen at: <http://asdeu.eu/wp2-activities/>.

Compliance with Ethical Standards

Conflict of interest The authors have no conflict of interest to declare.

Ethical Approval Ethical approval was given by the Research Ethics Committee of the University of Salamanca, Spain (201700008785).

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