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

Álvaro Bejarano-Martín, Ricardo Canal-Bedia, María Magán-Maganto, Clara Fernández-Álvarez, María Victoria Cilleros-Martín, María Cruz Sánchez-Gómez, Patricia García-Primo, Mary Rose-Sweeney, Andrew Boilson, Renata Linertová, et al.

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

Running Head:

Services for Young Children with ASD in Europe

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analysis or interpretation of the data, the writing of the manuscript, or the decision to submit the paper for publication.

Contributors

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.

Declarations of interest

All authors declare they have no conflicts of interest.

Ethical approval

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

Abstract

ASD provided services require to hear the opinion of both parents and professionals. However, rarely both opinions are gathered in the same research study and compared one to another. Hence, this study aims to ascertain the views held by families and

professionals on early detection, diagnosis and intervention services for young children with ASD. An online survey was conducted. A total of 2,032 from 14 European countries were collected (60.9% parents; 39.1% professionals). Using an ordinal scale from 1 to 7, the opinion of parents was more negative (mean=4.6; SD=2.2); than professionals (mean=4.9; SD=1.5) when reporting satisfaction with services. These results suggest services should necessarily take into account children's age, delays in accessing services and active participation of the stakeholders.

Keywords

autism spectrum disorder; early detection; diagnosis; patient satisfaction; mental health services; survey

Services for Young Children with ASD in Europe

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

ASD provided services require to hear the opinion of both parents and professionals. However, rarely both opinions are gathered in the same research study and compared one to another. Hence, this study aims to ascertain the views held by families and professionals on early detection, diagnosis and intervention services for young children with ASD. An online survey was conducted. A total of 2,032 from 14 European countries were collected (60.9% parents; 39.1% professionals). Using an ordinal scale from 1 to 7, the opinion of parents was more negative (mean=4.6; SD=2.2); than professionals (mean=4.9; SD=1.5) when reporting satisfaction with services. These results suggest services should necessarily take into account children's age, delays in accessing services and active participation of the stakeholders.

Keywords: autism spectrum disorder; early detection; diagnosis; patient satisfaction; mental health services; survey

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4 Autism spectrum disorder (ASD) is a neurodevelopmental disorder of early onset,
5
6 characterised by deficits in social communication, along with restricted and repetitive patterns
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8 of behaviour, interests or activities that have significant consequences in daily life (American
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10 Psychological Association, APA, 2013). When parents first begin to worry about their child's
11
12 developmental difficulties, they must make a considerable effort to seek answers to their
13
14 questions and obtain an accurate diagnosis. Furthermore, families have to face the challenge of
15
16 adapting to the new and unexpected reality of having a child with autism in the family, find
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18 appropriate treatment, reorganise family roles and pay for specialist treatments (DePape &
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20 Lindsay, 2015; Hock, Timm, & Ramisch, 2012; Keenan, Dillenburger, Doherty, Byrne, &
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22 Gallagher, 2010). Several studies indicate that parents of children with ASD report higher stress
23
24 levels and lower service satisfaction than do parents with children of other disabilities (Baker-
25
26 Ericzén, Brookman-Fraze, & Stahmer, 2005; Gray, 2006; Griffith, Hastings, Nash, & Hill,
27
28 2010; Hayes & Watson, 2013). Families with a young child with ASD report greater difficulties
29
30 in accessing services, higher associated costs and a lack of information and support during the
31
32 diagnostic process (Hodgetts, Zwaigenbaum, & Nicholas, 2015; Kogan et al., 2008; Thomas,
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34 Parish, Rose, & Kilany, 2012a; Wang, Mandell, Lawer, Cidav, & Leslie, 2013).

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43 **The challenges of these families** have been associated, not only with factors linked to the
44
45 child's characteristics, but also with family characteristics, socio-demographic factors and the
46
47 characteristics of service delivery. With regard to the socio-demographic aspects, observation
48
49 has shown that individuals with ASD belonging to families with a high parental socio-economic
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51 status (SES) and high parental educational level are diagnosed earlier, and that their families
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53 report greater satisfaction with the diagnostic process (Durkin et al., 2010; Goin-Kochel,
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4 Mackintosh, & Myers, 2006; Irvin, McBee, Boyd, Hume, & Odom, 2012; Moh & Magiati,
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6
7 2012; Thomas et al., 2012b).

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9 In relation to the services provided to young children with ASD, the sources of distress
10 and dissatisfaction mentioned by parents are professionals' tardiness in addressing their initial
11 concerns, delay in getting a diagnosis, and the lack of professional support (Altiere & Kluge,
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13 2009; Bishop, Richler, Cain, & Lord, 2007; Bluth, Roberson, Billen, & Sams, 2013; Crane,
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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 & Kluge, 2009; Bishop, Richler, Cain, & Lord, 2007; Bluth, Roberson, Billen, & Sams, 2013; Crane, Chester, Goddard, Henry, & Hill, 2016; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Moh & Magiati, 2012; Osborne, McHugh, Saunders, & Reed, 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, Stuart, & Auinger, 2006), inadequate organisation of care programmes (Chiri & Warfield, 2012), and the absence or scarcity of skilled professionals specialised in ASD (Krauss, Gulley, Sciegaj, & Wells, 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 both families and professionals, it is an irrefutable fact 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

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3
4 that improvement strategies should focus on the child and his or her family (McConachie et al.,
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6
7 2015; Pellicano, Dinsmore, & Charman, 2014). The purpose is to ensure that families are more
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9 actively involved in assessment of the child's and the family's needs, and that professionals take
10
11 a proactive approach to identify such needs. Families that report being actively involved in
12
13 decisions and have good communication with professionals also report greater satisfaction with
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15 services, fewer gaps in services, fewer delays in accessing treatment and services, lower stress,
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17 and lower general ASD-related costs (Kuo, Bird, & Tilford, 2011; Moh & Magiati, 2012; Burke
18
19 & Goldman, 2015). Likewise, recent studies have shown that, when professionals respond
20
21 promptly to parents' concerns, delays in access to diagnostic services are reduced and overall
22
23 satisfaction is increased (Zablotsky et al., 2017; Zuckerman, Lindly, & Sinche, 2015).
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29 **Nowadays social networks and institutional websites broadly use surveys as tools to**
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31 **explore the state of art about unmet needs services. These surveys are based on large number of**
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33 **responses and they constitute a cost-effective procedure for situation analysis and hypothesis**
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35 **generation, even though they fail providing inferences free of bias. However, they are excellent**
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37 **tools for analysing large and diverse populations.**
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41 Although the opinions and satisfaction of families and professionals with early
42
43 detection, diagnosis, and early intervention services seem to have played a fundamental role in
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45 changing policies and improving services for the ASD community, the perspectives of these
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47 two different groups have rarely been considered together. Hence, it is important to obtain
48
49 detailed information about the type of services which young children with ASD receive and the
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51 views held by various European stakeholders on such services, in order to inform the decisions
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53 of policy makers -at both a national and European level- affecting the financing of services and
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55 training of families and professionals.
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4 To this end, we used the Autism Spectrum Disorder in the European Union (ASDEU,
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6 2015-2018) network to conduct a multinational study aimed at assessing and collecting the
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8 opinions and attitudes of the autism community (families and professionals) concerning early
9
10 detection, diagnosis and intervention services for children with ASD under 9 years of age in 14
11
12 European countries. More specifically, our objectives with regard to early detection, diagnosis
13
14 and intervention services were: (a) to identify the types of services received by children with
15
16 ASD in Europe; (b) to examine families' and professionals' degree of satisfaction with services
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18 across Europe; (c) to explore variations in age at detection, diagnosis and intervention and
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20 delays in accessing services, as reported by parents and professionals; (d) to identify the
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22 variables that predict service satisfaction in both groups; and lastly, (e) to identify service
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24 differences between European regions according to per capita income.
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33 **Methods**

34 *Survey development*

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38 The design and development of the surveys was carried out in three phases. The first
39
40 phase consisted in creating a focus group activity aimed at obtaining initial direct information
41
42 about the perceptions and ideas of people normally involved in the processes of detection,
43
44 diagnosis, and early intervention of children with ASD. This information helped us to delimit
45
46 the content and topics of interest that we were going to include in the surveys. The second phase
47
48 focused on the development of the items and the structure of the questionnaires. The last phase
49
50 consisted of a controlled distribution of the survey (pilot study) to a group of families and
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52 professionals with the purpose of identifying difficulties in understanding the items and
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54 evaluating the functioning of the survey.
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Focus groups

During the first phase, 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 (Bulgaria, Denmark, Finland, France, Iceland, Italy, Poland, Portugal, Romania, and Spain) conducted two focus group sessions addressing each of these two topics. 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, autism knowledge that participants attribute to professionals, services limitations (economic, material resources, trained personnel), family participation in the diagnostic process and during the treatment activities, the best known practices by 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 the data into categories and sorting the ideas, perceptions, concerns,

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4 and interests expressed by the participants. This set of categories enabled the elaboration the
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6 items of the questionnaires items and differentiate the surveys questions directed to families and
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8 the questions directed to professionals. Following this procedure, two different surveys were
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10 drawn up to facilitate collection of data from the two respondent groups, namely, parents or
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12 family members and professionals who were directly related to a child with ASD, (See
13
14 Appendixes 1 and 2 for **Final Survey English Version**).

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19 Section one collected basic information about respondents' gender, age, country and city
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21 of residence. In addition, family members were asked about their relationship to the child,
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23 academic attainment, number of people living permanently in the household, and the gender,
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25 age, diagnosis and verbal ability of the child. Professionals, on the other hand, were asked about
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27 their main job and their experience in working with children with autism.
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31 Sections two to four contained questions on early detection, diagnosis and early
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33 intervention respectively. Both the family member and professional surveys included a brief
34
35 introductory explanation of the type of questions that the respondent would have to answer.
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37 Professionals were asked whether they were directly involved in any programme dealing with
38
39 early detection, diagnosis or early intervention. Those who responded negatively to these
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41 questions were asked to provide contact details of someone involved in such programmes and
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43 then directed to the next section of the survey. The questions were intended to elicit specific
44
45 data on the processes of detection, diagnosis and beginning treatment, from the moment when
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47 families or professionals first began to worry until the time when the specialist treatment began.
48
49 Respondents were thus asked about the age of the child when concerns first arose (detection),
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51 age at diagnosis and age when treatment or intervention started, as well as any delays in access
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53 to services, types of professional involved in the different processes, type of diagnosis, degree
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4 of family involvement at each stage, type of intervention, and the like. Therefore, the survey
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6 included specific questions about satisfaction with detection, diagnosis and intervention
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9 (Appendixes 1-2).

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11 The principal response categories were: (i) age of the child at the time of accessing to
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13 detection, diagnosis and intervention services (families: list from 0 to 9 years; professionals:
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15 based on the following ranges). The answers were stratified as 0-18, 18-24, 24-36, and > 36
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17 months at detection; 0-18, 18-32, 32-46, 46-60, and > 60 months at diagnosis and intervention.
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19 (ii) Delays in access to services ranging between 0-3 months, 3-6 months, > 6 months. (iii)
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21 Assessment the satisfaction with services on a scale of 1 to 7 (1: extremely inadequate; 2:
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23 moderately inadequate; 3: slightly inadequate; 4: neither adequate nor inadequate; 5: slightly
24
25 adequate; 6: moderately adequate; 7: extremely adequate). The different answer choices for all
26
27 aforementioned questions were then stratified and recoded into three new categories: negative
28
29 (from 1 to 3), neutral (4), and positive (from 5 to 7). (iv) The level of parent participation in the
30
31 intervention sessions was stratified into two categories: active participation (very actively and
32
33 actively participation responses) and occasional/no participation (occasional participation and I
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35 don't participate responses).

46 *Survey testing*

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48 After translation and adaption by researchers from the respective countries involved in
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50 the project, 14 country-specific versions of the survey were produced (See Table 1). The
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52 process included the use of official translations of some questions (e.g., intervention
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54 programmes, manuals, etc.) when available in each country. The translations were uploaded to
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56 the Qualtrics web platform (<https://www.qualtrics.com>).
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4 Before the surveys were publicly launched, they were piloted in three countries (Spain,
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6 Denmark and Iceland) with the support from twelve parents from six family' organisations, five
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8 professionals from the ASDEU project network and three professionals not directly related to
9
10 the project. Parents 12 (60%) and professionals 8 (40%) were asked to give their opinion on the
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12 content, format and accessibility of the surveys. All pilot respondents reported that the survey
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14 was accessible and that the questions were clear and comprehensible, indicating no need to
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16 further adapt wording or length of questions. Participants completed the survey in 15-20
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18 minutes. The Flesch reading Ease was 60.8 and the Flesch-Kincaid Grade Level (Kincaid,
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20 Fishburne, Rogers, Chissom, 1975) was 8 (word office tool). These scores were within the
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22 standards for a document to be accessible and easy to read for the population.
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31 *Recruitment procedure*

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33 The survey was made available online and distributed by researchers affiliated to the
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35 ASDEU project website in the 14 participating countries. Clinical practitioners as well as
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37 parents' and professionals' organisations promoted the survey through their own networks.
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39 Professionals were asked to distribute the survey to family members of children under nine
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41 years old receiving a treatment for ASD and give them guidance on how to respond. Invitations
42
43 to participate in the survey were also sent to websites visited frequently by the ASD
44
45 community, i.e., service providers, private and public associations, Facebook groups, Twitter,
46
47 bulletins, etc. In addition, links to the survey were provided in the online newsletter of the
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49 ASDEU project (<http://asdeu.eu/newsletter/>). Special education schools, rehabilitation centres
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51 working with children with neurodevelopmental problems, psychiatry services for children and
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adolescents, home guidance centres and residential centres for children with ASD participated in the surveys and disseminated them to families.

Although a total of 3,693 people initiated the survey, only 2,032 respondents met the inclusion criteria (Tables 1 and 2). The reasons for exclusion of the remaining 1,661 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. Countries with fewer than five respondents were included in the sample but country-specific statistics are not reported.

[Place Table 1 here]

[Place Table 2 here]

The family group was the larger of the two respondent groups, with 1,237 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 total 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 five years' experience in that job.

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 carried out.

Multinomial regression analyses were conducted to compare parents and professional reports in 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. The main objective of this comparison was to know which type of participants reported lower access ages and if these differences were statistically significant ($p < 0.05$). (ii) Similarly, delay in access to service was compared between parents and professionals to know who reported the longest waiting times. The analysis was conducted to examine the likelihood of the child having less delays in access to detection, diagnostic and intervention services. (iii) Satisfaction with services about questions relating to respondent's opinions regarding detection, diagnostic and intervention, with respondents being asked to report the degree of adequacy of the services to examine the likelihood of positive satisfaction (vs negative satisfaction). Interaction terms in the models were used to explore differences between families and professionals, considering the

respondents' sex where appropriate. To this, separate analyses were performed for professionals and families (family male vs family female; professional male vs professional female). (iv) Finally, parent participation was associated to intervention satisfaction. The main goal of this analysis was to know if active parent participation resulted in a more positive satisfaction with the services. The different answer choices for these questions were collapsed to examine the likelihood of positive satisfaction (vs negative satisfaction) about parent participation (active participation vs occasional/no participation).

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 following independent variables: (1) age of detection (0-18 months), diagnosis (0-24 months), and intervention (0-36 months); and (2) delays in accessing these services (>6 months). The analyses were obtained with the total sample for each group of participants separately.

Results

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., 2014)). Both respondent groups reported that the professionals most frequently involved in the detection and diagnostic processes were those working in mental health services. This group

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4 most frequently informed families about the educational needs of the child. Professionals
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6 reported that they informed families about the child's specific needs, highlighting the
7
8 educational needs. Caregivers also reported this, however, noteworthy 20% of the families
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10 reported that they did not receive any information (e.g., medical or educational needs) at the
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12 time of the child's diagnosis.
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16 Most family respondents indicated that they were not involved (40%) or only
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18 occasionally involved (30%) in the intervention process, whereas 70% of professional
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20 respondents reported that parents participated actively in interventions. Only 13.1% of
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22 professionals appointed that they had not provided parents with information about intervention
23
24 programmes when their child started treatment. Family respondents indicated that the most
25
26 commonly recommended interventions were speech therapy, physiotherapy and parental
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28 training sessions. Specific intervention programs for people with ASD were available to 24% of
29
30 the family participants. The number of sessions that children with ASD received according to
31
32 their families was lower than the number of sessions reported by professionals. Both groups
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34 reported that the majority of sessions that children with ASD received were individual sessions.
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36 The distance and time to reach the intervention services varied greatly, ranging from 1 to 100
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38 kilometres and 1 to 60 minutes.
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48 *Age at detection, diagnosis and intervention, and delay in access to services*

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51 According to family respondents, the average age at which concerns were first raised
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53 about the child who was later diagnosed with ASD, was 18.3 (*SD* 13.4) months. The average
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55 age at diagnosis was 36.4 (*SD* 17.7) months, with most diagnoses occurring between 32 and 46
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57 months according to both families and professionals. Professionals reported that the age of most
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4 detected cases ranged from 24 to 36 months. Average age of starting an early-intervention
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6 programme reported by families was 42.2 (*SD* 15.4) months (Table 2).
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10 Detection of symptoms appearing before the age of 18 months were more likely reported
11
12 by families respondents compared to professionals. Also, families were more likely than
13
14 professionals to report a detection delay of over 6 months (Table 3). Again, most families
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16 reported a delay in the access to diagnostic services of over 6 months, compared to 3-6 months
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18 reported by professionals. However, professionals more often than families reported a longer
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20 delay -of over 6 months- in access to intervention services.
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24 [Place Table 3 here]
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29 *Satisfaction with services by sex and group (parent vs professional) and by parental*
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31 *involvement (active vs occasional/no participation)*
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34 The sample size for these analyses was 2,032. Figure 1 illustrates the mean rankings
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36 (from 1: extremely inadequate, to 7: extremely adequate) provided by each male and female
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38 respondent in each respondent group. Rankings indicate significant differences between
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40 respondents by group (families/professionals) and sex. Families were more likely to express less
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42 positive satisfaction (scale from 4 to 7, see Figure 1) than professionals for all items evaluated
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44 (Table 4). Regarding detection, we found greater differences between families and
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46 professionals in the evaluation of the general process, as well as in the degree to which the
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48 professionals took into account the family's concerns. Regarding diagnostics, the greatest
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50 differences were found in the general evaluation of the process, in addition to the professional
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52 level of the team involved. Moreover, when appraising the intervention differences between
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54 families and professionals about the information and support received, as well as the number of
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sessions, in the evaluation of the intervention were also found, as previously noted in the description of the services reported by families and professionals. (See Table 2).

[Place Table 4 here]

[Place Figure 1 here]

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). (Figure 1; Table 4).

Comparisons across participants regarding intervention sessions participation (actively vs occasional/no participation) and service assessment were conducted. Families who were actively involved were more likely to express more positive satisfaction with the intervention process than families who did not participate or only participated occasionally (Table 4). This 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

Families of children who reported to have been detected at an early age and who had less delay in accessing this service were more likely to express higher family positive satisfaction with detection services (scale from 4 to 7, see also Figure 1). Table 5 shows the odds ratios (ORs) for each predictor vis-à-vis each outcome measure of satisfaction (See

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4 Appendix 3 supplementary material, all items evaluated separately). By reducing the age of
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6 detection, the perception of detection services would be more positive in all items for families.
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8 In addition, families who reported delays in access an early detection service of more than 6
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10 months assessed the process worse. On the other hand, professionals who reported early child's
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12 age of detection were more likely to express higher positive satisfaction in any of the items
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14 related to the assessment of detection services (Table 5).
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24 The results for diagnostic services follow a similar pattern to screening services for
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26 families only. Families who reported less delay in access to detection and diagnostic services
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28 were more likely to express higher satisfaction, while professionals who reported earlier child's
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30 age of diagnosis and less delays in access to this service were not more likely to express higher
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32 satisfaction with diagnostic services (Table 5).
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36 Finally, the results indicated that the same families of children who reported shorter
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38 delays in access to detection, diagnosis and early-intervention programmes were more likely to
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40 express higher family positive satisfaction of intervention services. Therefore, by reducing the
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42 delay in access to detection, diagnosis and intervention, the assessment of intervention services
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44 would be more positive. On the other hand, professionals who reported earlier child's age of
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46 intervention and less delays in access to this service were not more likely to express higher
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48 positive satisfaction in any of the related items. (See Table 5 and Appendix 3).
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57 Discussion 58 59 60 61 62 63 64 65

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4 The aim of this study was to analyse the characteristics of detection, diagnosis and
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6 intervention services received by children with ASD, and to compare and contrast the overall
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8 satisfaction reported by 1,223 families and 760 professionals, in order to provide an evidence
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10 based framework for clinicians, decision-makers and researchers to consider, and so enable
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12 them to incorporate the views of these groups into their activities. The overall satisfaction of
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14 participants was positive (>4 on the scale) for all early detection, diagnosis and intervention
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16 items evaluated (Figure 1). Survey participants seem to be more engaged in the process than
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18 non-respondents, and more likely to have had positive experiences with services, as well as
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20 more positive attitudes of the participants (Keusch, 2015). Although overall satisfaction was
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22 positive, professionals were more satisfied than family members (Table 3). These differences
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24 could be due to the fact that families have to deal with the process not only of gaining
25
26 recognition and acceptance of the fact that there is something wrong with their child's
27
28 development, but also of waiting for services, as well as the sheer amount of services and
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30 medical visits that children with ASD need, all of which results in higher levels of stress (Burke
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32 & Goldman 2015; Summers et al., 2007). In addition, differences could be due to the fact that
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34 families respond based on their personal experiences, while the professionals respond based on
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36 the experiences with all the parents they attend. Whereas providers might recognize that delays
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38 in the diagnosis or the onset of services is not optimal, they do not experience the frustration
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40 experienced by families, accumulated each month. Therefore, these differences should be taken
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42 carefully, due to the great dissimilarity of the process experience of each group. For instance,
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44 significant differences were found in satisfaction with the number of intervention sessions
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46 (Table 4). Based on their experience, parents reported receiving less than half the time in
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48 intervention sessions than what reported by professionals, which would show how the personal
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4 experiences lived in the services could affect satisfaction. Dissatisfaction with the information
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6 provided by practitioners, the support received and the delays in access to services observed in
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8 this study is consistent with the findings of previous studies (Dymond, Gilson & Myran, 2007;
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10 Hodgetts, 2015; Liptak et al., 2006; Ngui & Flores, 2006; Rogers, Goddard, Hill, Henry, &
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12 Crane, 2016). However, no previous studies have shown differences between family members
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14 and professionals in terms of satisfaction with detection, diagnosis and intervention services.
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19 Future studies should therefore focus on the reasons for these differences.
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22 The ages of detection, diagnosis and access to intervention reported by family members
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24 are markedly lower than those reported in some previous studies (Baio et al., 2018; Oswald,
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26 Haworth, Mackenzie, & Willis, 2017) but similar to those reported in others (Adelman &
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28 Kubiszyn, 2017; Daniels et al., 2017; McIntyre & Zemantic, 2017; Moh & Magiati, 2012). It is
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30 possible that the variation in families' reports of age at first access to services for children with
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32 ASD simply reflects differences in socio-economic status, since it has been observed that
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34 families with greater socio-economic resources enjoy better access to services and specialists.
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36 Families with low socio-economic resources tend to report higher ages of access to services
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38 (Kalkbrenner et al., 2011; Liptak et al., 2008). Another possible explanation lies in differences
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40 in parent awareness of their child's early difficulties (Daniels & Mandell, 2014; Sacrey et al.,
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42 2015; Zablotzky et al., 2017; Zuckerman et al., 2015). In this study, 70% of families reported
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44 having had some concerns about the development of the child who was subsequently diagnosed
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46 with ASD, something that may have reduced the age of detection and diagnosis, and thus
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48 speeded up access to an intervention programme. Families reported that the average delay
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50 between detection and diagnosis (18.1 months) was much longer than between diagnosis and
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52 treatment (5.8 months), and 14.8% of families reported that their child had started an
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4 intervention programme (private or public) before receiving a formal diagnosis. Another
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6 possible explanation could be that in this type of surveys the participants were more aware and
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8 had greater resources, both personal and material assets. The recruitment process for the survey
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10 was carried out in parent associations, as well as in other ASD specific services, participants
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12 may have had access to resources such as diagnosis or intervention, which would reduce
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14 significantly delays to these services. Parents who are more engaged are more likely to be
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16 concerned earlier and to have experienced relatively greater delays in accessing diagnosis for
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18 example. Future studies should investigate whether satisfaction with services is more closely
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20 linked to the length of delays in access or to the age at which the child obtains access to
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22 services.
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29 Differences between families and professionals could be related to their differing
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31 experiences. In their recent experience, professionals may have conceivably dealt with cases
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33 where diagnosis was made quite early and delays in access to services were short, with the
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35 result that these recent positive experiences may have influenced their estimation of the
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37 promptness with which services respond to parents' concerns. However, the fact that families
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39 reported tardier and slower responses than did professionals would suggest that service lags
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41 exist and there is a need to provide professional staff with technical and human resources
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43 (training programmes and tools) which will speed up the detection and diagnostic processes and
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45 reduce delays in access to such services.
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51 Families who had early access to services and experienced fewer delays tended to rate
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53 services more positively. These results are consistent with studies such as those by McKenzie et
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55 al. (2011) and Kuo et al. (2011), where parents who reported the greatest satisfaction with the
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57 information and support received were those whose child had been younger at the time of
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4 diagnosis. Most of the families that participated in the study reported that, after becoming
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6 concerned about their child and communicating their concerns to a paediatrician, they had to
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8 wait, first for a diagnosis of ASD from a specialist service and then for an intervention
9
10 programme. In contrast, professionals' evaluations were more positive and more uniform than
11
12 those of families, and they reported that waiting times were shorter and children younger when
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14 they gained access to services. This could be explained by considering that families must go
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16 through the entire process, from detection to intervention, while professionals may just be
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18 involved in one of all these services. Therefore, the experiences of family members, who have
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20 to go from one service to the other will tend to be more negative.
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26 An important finding related to detection is that very few families reported participation
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28 in ASD-specific screening programmes (3.1%), also according with previous studies Adelman
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30 and Kubiszyn (2017) and reported experiences in Europe (García-Primo et al 2015). However,
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32 70% of families reported having expressed concerns to different professionals, which would
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34 imply the start of a development screening program. Therefore, detection was primarily based
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36 on the experience and knowledge of the professional. Use of an effective and efficient screening
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38 tool would allow professionals to detect potential ASD cases at an earlier age and refer them to
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40 diagnostic services earlier, thus reducing the delay between detection and diagnosis, which can
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42 be as long as 18 months, according to families. Reducing the delay in diagnosis would enable
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44 children to begin intervention programmes earlier. If intervention occurs early, when neuronal
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46 plasticity is much greater, long-term positive results can be achieved (Crais & Watson, 2014a).
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48 It has been widely reported by paediatricians that there are many barriers to detection of ASD
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50 and the use of population screening programmes (Crais et al., 2014b), and there have been
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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 & Zemantic, 2017; Stadnick, Drahota & Brookman-Fraze, 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 & Wainer, 2013; Kasari, Gulsrud, Paparella, Helleman, & Berry, 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, Shannon, Berger, Pickard, & Holtz, 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 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 & Salzer 2007; Thomas 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 & Ingersoll, 2017; Liptak et al., 2008; Weiss, Cappadocia, MacMullin, Vecili, & Lunskey, 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

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4 unrepresentative of the general community (Salomone et al., 2015). Although online surveys are
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6 commonly used and the limitations associated with them are well known, it is possible that our
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8 results cannot be generalised to populations with lower socio-economic levels. Sample size
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10 differed from country to country, and consequently countries with large samples may not be
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12 representative of all the countries that were included within a given category. An additional
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14 limitation of our sample was that we did not have parental and professional ratings for the same
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16 individual. Future research should therefore compare the views of families and professionals
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18 about the *same* children with ASD, in order to have a more accurate picture of the differences
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20 found in this study.
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26 The dissemination was the same in all countries, but parent' organizations, special
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28 education schools, ASD specialized centres, etc. were not exactly alike in all countries, and
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30 thus, they may have had different policies. Therefore, the participants who were invited to
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32 complete the survey may not be the same in all countries, hence increasing the variability of the
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34 results. Another source of variability was the type of participants who completed the surveys.
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36 Since the surveys were distributed mainly in services for individuals with ASD, it is likely that
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38 highly engaged families with knowledge of ASD, as well as professionals with a high degree of
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40 experience, were the largest group of surveys participants (Table 2). Satisfaction with processes
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42 and services is usually assessed through surveys. These are so-called "self-selection" surveys
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44 (Bethlehem, 2010) which are not based on probabilistic sampling. The survey is simply
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46 uploaded to a secured website and respondents are those who have access to the Internet and
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48 visit the website. In our specific case participants would visit the website because they must
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50 have had some interest in autism and decided to participate in the survey. As a consequence,
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52 participants are usually parents and professionals who are committed in some way to autism,
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4 but also with a higher level of education, and with more economic resources relative to the
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6 general population (Bethlehem, 2010; Infante-Rivard and Cusson, 2018). Assuming this reality,
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8 the results of self-selection web surveys can be considered representative when there is a large
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10 number of respondents, or as a result of using advanced adjustment weighting procedures in the
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12 methods of analysis (Bethlehem, 2010). Future studies should compare these results with those
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14 that can be obtained by surveying parents (or family members) less involved in services and
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16 professionals with less ASD specific experience.
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21 Another potential sample limitation is that, since the recruitment system was online and
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23 anonymous, we were unable to ascertain why some potential respondents decided not to
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25 participate. A total of 1,661 people started but did not complete the survey, without it being
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27 possible to establish why they failed to complete it once they had begun (e.g., due to connection
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29 or computer problems, lack of time, distractions, etc.). It is however reasonable to assume that
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31 those who decided to complete the survey were the most committed and competent respondents,
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33 and that, by extension, may thus not be representative of the autism community as a whole
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35 (Fletcher-Watson et al., 2017).
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41 Moreover, our data were mostly derived from responses to closed questions, which
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43 compel the respondent to select from a fixed, restricted set of answers. Use of this question
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45 format was necessary for several reasons, such as the international nature of the survey, and the
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47 accompanying lack of translation resources to translate respondents' answers to open-ended
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49 questions. Ultimately it was a compromise, whereby the restriction on response options enabled
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51 us to collect data from a larger sample of the autism community.
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55 Lastly, another factor affecting the range and access to services for children with ASD is
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57 location (rural, urban etc.). The location of the nuclear family has a significant impact on the
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4 number of services and professionals available (Murphy & Ruble, 2012). Family and
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6 professional survey participants reported residing in urban areas. Future research should study
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8 these relationships in a more representative sample, so as to be able to provide the best
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10 recommendations, taking into account the particular characteristics of each family and the
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12 points of view of the professionals concerned.
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18 *Conclusions*

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23 Our results indicate that, though families and professionals in the autism community are
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25 broadly satisfied with services and that children's ages were lower and delays in access to
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27 services were shorter than in other studies, differences were nevertheless found between these
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29 two groups. In particular, families of children with ASD reported lower overall satisfaction with
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31 and higher child ages and longer delays in access to services than did professionals who
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33 routinely work with children with ASD. Notwithstanding this, the results suggest that, in both
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35 families and professionals, greater satisfaction with services is associated with low ages of
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37 detection and diagnosis, as this enables intervention to begin sooner. The clearest message from
38
39 this study is that it is parents who are still crucial for the detection of the first ASD signs.
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42 Families are telling us that there is a need of collaborative, inclusive and self-critical
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44 professionals, and that they should be involved in every aspect of care for their child. Service
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46 policies and future research should focus on reducing delays in access to services, through, say,
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48 the implementation of early ASD-specific detection programmes, in order to increase families'
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50 satisfaction with services and thereby possibly reduce their stress and improve their wellbeing.
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Notes

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

Compliance with Ethical Standards*Funding*

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Disclosure of potential conflicts of interest

The authors have no conflict of interest to declare.

Ethical approval

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

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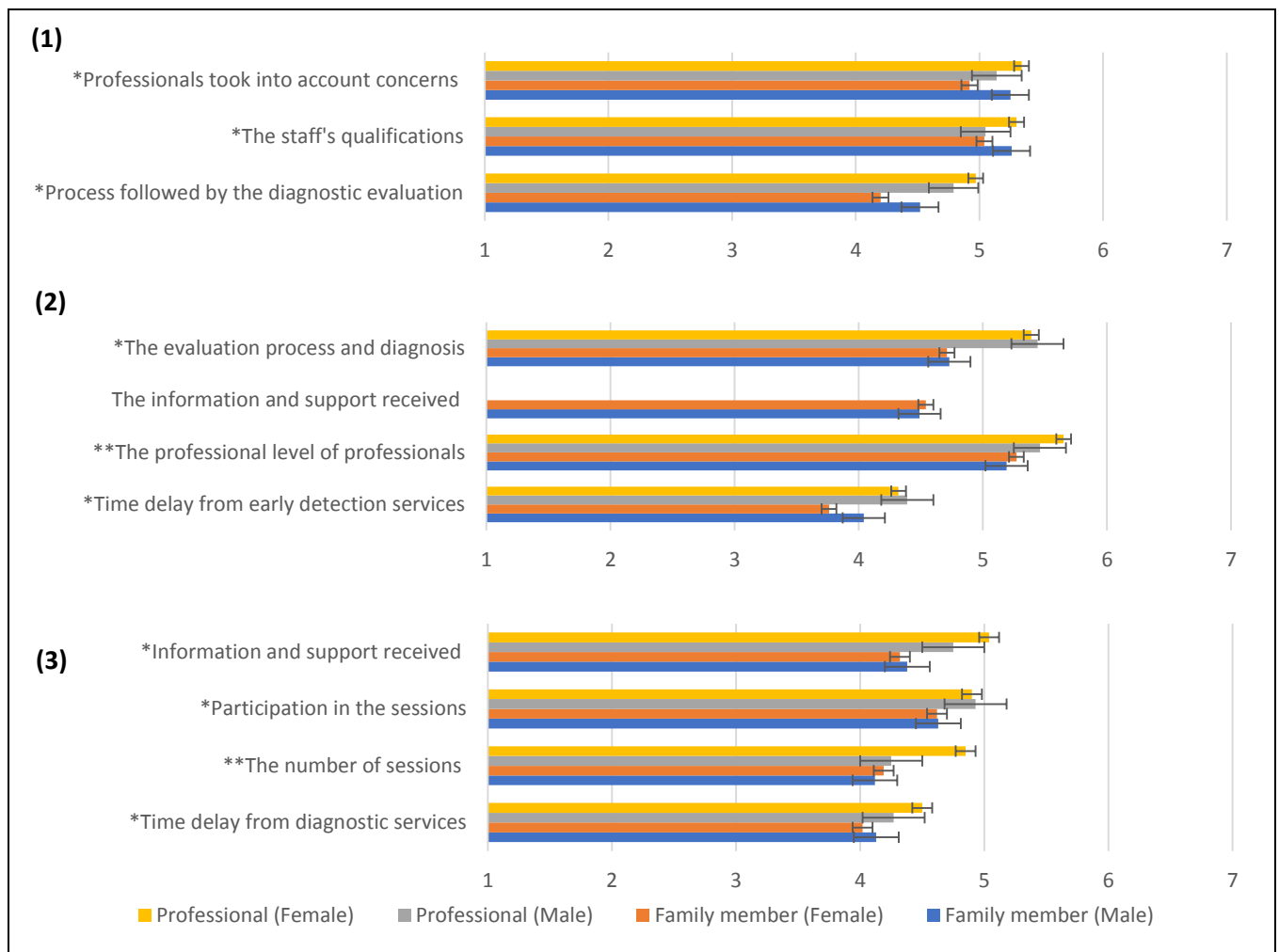
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Figure 1. Average opinion of services by family and professional respondents by sex

(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; $p < 0.05$

Table 1. Sample size by respondents' country according to gross domestic product (GDP) category

	Family members <i>n</i> = 1237	Professionals <i>n</i> = 795		Total <i>N</i> = 2032 (%)
Very high GDP (>40,000 €)	306	373	677	33.3%
Iceland	50	45	95	4.7%
Ireland	79	15	94	4.6%
Denmark	94	96	190	9.4%
The Netherlands	6	4	10	0.5%
Austria	23	12	35	1.7%
Finland	52	200	252	12.4%
Other*	2	1	3	0.1%
High GDP (30.000-40.000 €)	285	183	468	22.9%
Belgium	159	40	199	9.7%
Great Britain	19	1	20	1.0%
France	105	140	245	12.0%
Other*	2	2	4	0.2%
Medium GDP (20.000-30.000 €)	367	148	515	25.2%
Italy	86	30	117	5.7%
Spain	278	116	393	19.4%
Other*	3	2	5	0.2%
Low GDP (<20.000 €)	279	91	370	18.2%
Portugal	25	10	35	1.8%
Poland	222	79	301	14.8%
Romania	28	-	28	1.4%
Other*	4	2	6	0.3%

*Countries in the "Other" category: very high GDP (Norway, Switzerland); high GDP (Germany); medium GDP (Malta, Cyprus, Slovenia); low GDP (Hungary, Croatia, Russia, Macedonia).

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*)	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%
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

* Grandparents, siblings

All percentages exclude missing values.

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 ^a	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 ^a	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

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 $p < .05$ are indicated in bold (-) Not applicable. Not asked or not possible to calculate

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

^b Reference group in the multinomial logistic regression.

Table 5. Predictors of positive satisfaction

	Detection	Diagnosis	Intervention
	OR (95% CI)	OR (95% CI)	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)

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