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## Determinants of satisfaction with the detection process of autism in Europe – Results from the ASDEU study

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## Abstract

Satisfaction with the detection process of autism and its determinants were investigated using data from the Autism Spectrum Disorder in the European Union (ASDEU 2015-2018) network. A total of 1,342 family members, including 1,278 parents, completed an online survey collecting information about their experience and satisfaction with the early detection of autism in their child. Overall, the level of satisfaction varied considerably from one respondent to another. Difficulty in finding information about detection services, lack of professional guidance and support in response to first concerns, finding a diagnostic service on one's own, and a delay of more than 4 months between the confirmation of concerns and the first appointment with a specialist were all experiences individually associated with greater odds of being less satisfied. Using a dominance analysis approach, we further identified professional guidance and support in response to first concerns as the most important predictor of the level of satisfaction. These findings highlight aspects of the process that need to be improved in order to enhance the experience of the detection process and are therefore relevant to guide health administrations towards actions to be implemented to this effect.

**Keywords:** Autism, Early detection, Parents' experiences, Satisfaction

**Lay Abstract**

Professional guidance and support in response to first concerns appears to be an important predictor of the level of satisfaction with the detection process of autism in young children. In this study, we analyzed the views of 1,342 family members, including 1,278 parents, who completed an online survey form collecting information about their experience and satisfaction with the early detection of autism in their child. Specifically, we were interested in how specific experiences with the detection process relate to the satisfaction with it and whether we could identify important predictors of satisfaction. The detection process is an emotionally charged period for parents, often described as painful, chaotic and lengthy. A better understanding of their experiences is important in order to take appropriate action to improve the detection process. In our sample, the level of satisfaction with the detection process varied greatly from one respondent to another. Among the different experiences we considered, whether or not respondents received professional guidance and support in response to first concerns explained most of this variation. We also found that difficulty finding information about detection services, lack of professional guidance and support in response to first concerns, having to find a diagnostic service on one's own, and longer delays between confirmation of concerns and first appointment with a specialist were experiences associated a greater likelihood of being unsatisfied. The findings of this study highlight the importance of the parent-professional relationship in the detection process and have important practical implications for health administrations to improve the detection process.

## Introduction

Over the past two decades there has been a growing interest in the early detection and diagnosis of autism. Early detection and diagnosis can promote early access to health and social services tailored to the specific needs of the child and family. Retrospective and prospective studies have now confirmed that most children who receive a diagnosis of autism show detectable early signs well before the syndromic stage of the condition (Jones et al., 2014; Zwaigenbaum et al., 2013). Diagnostic stability coefficients ranging from 63% to 100% have been reported, indicating that most children diagnosed at an early age (< 3 years) retain their initial diagnosis at later ages (Ozonoff et al., 2015; Pierce et al., 2019; Zwaigenbaum et al., 2016). In addition, developmental and relationship-based interventions, emphasizing the central role of parents and promoting naturalistic learning to support very young children, have been developed with some benefits reported in social communication skills and child development (Kasari et al., 2006; Pickles et al., 2016; Rogers et al., 2019; Zwaigenbaum et al., 2015). Within this context, implementing strategies to improve early detection and diagnosis services has become a priority objective of public health policies in many countries and autism guidelines and practice parameters are regularly released to help professionals and families navigate the process of detection, referral and diagnostic assessment of autism in young children (e.g. Haute Autorité de Santé, 2018; National Institute for Health and Care Excellence, 2011; Fuentes et al., 2006, 2020).

The detection process (i.e. the period from the onset of initial concerns to the diagnostic assessment) typically entails several steps that parents must go through in order to obtain a diagnosis for their child and access services. When asked about their experience of the detection process, parents often describe a painful, chaotic and lengthy process associated with high levels of stress, frustration and uncertainty (Boshoff et al., 2018; DesChamps et al., 2020; Legg & Tickle, 2019; Makino et al., 2021). Parents are usually the first to notice that something is different in their

child's development (Wong et al., 2017). This can occur as early as 12 months and usually involves language delays and social interactions, or general behavioral problems (Crane et al., 2016; Howlin & Moore, 1997). This period is marked by confusion with respect to the child's behavior, often with associated feelings of guilt and self-blame (Boshoff et al., 2018; Howlin & Moore, 1997). Several months may pass before parents decide to share their concerns to a professional (Crane et al., 2016). When seeking support and guidance, their concerns can be minimized or even ignored, some professionals opting for a passive 'wait and see' approach, others falsely reassuring parents telling them 'not to worry' that the child will 'grow out of it' eventually (Gentles et al., 2019; Ryan & Salisbury, 2012; Smith-Young et al., 2020). Important delays can occur at this point and some parents may look for diagnostic services themselves to accelerate the process and to overcome their sense of helplessness (Ryan & Salisbury, 2012). Even when professionals do not minimize or ignore parents' concerns and are proactive in their response, parents may still face long wait times to access diagnostic services or have to consult multiple professionals before a final diagnosis is made (Goin-Kochel et al., 2006; Moh & Magiati, 2012). Stress levels can increase dramatically during this period as the sense of urgency to obtain the diagnostic and access services increases (Boshoff et al., 2018; DesChamps et al., 2020).

Compared to parents of children diagnosed with other developmental conditions, parents of autistic children are more likely to experience longer delays and their concerns are more likely ignored, minimized or taken less seriously (Oswald et al., 2017; Zuckerman et al., 2015). Although the length of the delay varies greatly from parent to parent, average delays of more than 3 to 4 years between parents' initial concerns and diagnosis have been reported in Europe (Crane et al., 2016; Höfer et al., 2019). Delays may occur at different stages of the process and may result from a variety of factors, including heterogeneity in clinical presentation, socioeconomic and ethnic disparities in access to and use of health services, availability of services in the area of residence, as well as the attitude and response of professionals to parental concerns (Bent et al., 2020; Boshoff et

al., 2018; Crane et al., 2016; Daniels & Mandell, 2014; Gibbs et al., 2019; Wong et al., 2017). Not surprisingly, many parents hold negative views about the detection and diagnosis processes (Chamak et al., 2011; Crane et al., 2016; Goin-Kochel et al., 2006; Höfer et al., 2019; Howlin & Moore, 1997; Makino et al., 2021). They often express the need for a simplified, more consistent and systematic process as well as greater training and awareness about autism for professionals (Osborne & Reed, 2008). Although most studies have been conducted in the UK and the US, negative views and experiences are similarly reported abroad, including France, Sweden, Germany, Singapore, New Zealand or Mexico (Carlsson et al., 2016; Chamak et al., 2011; Eggleston et al., 2019; Höfer et al., 2019; Moh & Magiati, 2012; Zavaleta-Ramírez et al., 2020).

However, it is also equally important to acknowledge that not all parents hold a negative view about the detection process, with some even reporting high satisfaction (Howlin & Moore, 1997; Locke et al., 2020; Wong et al., 2017). That some parents may be dissatisfied and others satisfied suggests that there are wide variations in the experience of the detection process across parents. Although the concept of satisfaction is subjective, i.e. for the same process, some parents may be satisfied while others may be dissatisfied, it does provide information about how the experience of the detection process relates to the parent's expectations about it (Thompson & Suñol, 1995). Depending on the magnitude and direction of the difference between the expectations and the actual experience of the detection process, the satisfaction level will be affected. Satisfaction levels are low when expectations are higher than the actual experience of the detection process and vice versa. Since parents' experience of the detection process is likely to have long-term consequences on their acceptance of the diagnosis as well as on their confidence in professionals and services, improving the experience of the detection process is an important objective to pursue (Osborne & Reed, 2008). Identifying factors associated with the level of satisfaction could provide valuable information to improve the detection process and increase the general level of satisfaction with it.



To date, multiple factors have been associated to the level of satisfaction with the detection and/or diagnostic process (Makino et al., 2021). Some are directly related to the experience of the process itself. For example, lengthy delays are usually associated with lower levels of satisfaction (Bejarano-Martín et al., 2020; Crane et al., 2016; Eggleston et al., 2019; Goin-Kochel et al., 2006; Höfer et al., 2019; Howlin & Moore, 1997). Conversely, parents are more likely to be satisfied if they positively rate the professional's manner, the initial reaction to their concerns, the quality of the information provided to them, or their perceived collaboration with the professional (Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012). Moh and Magiati (2012) even suggested that the attitude of professionals could be more important in determining parental satisfaction than the number of professionals consulted or the duration of the process (Moh & Magiati, 2012). On the other hand, family-level characteristics including parent level of education (Goin-Kochel et al., 2006; Hidalgo et al., 2015), level of stress (Crane et al., 2016; Eggleston et al., 2019; Moh & Magiati, 2012), or family income (Goin-Kochel et al., 2006; Hidalgo et al., 2015), as well as child-level characteristics such as final diagnosis (Howlin & Moore, 1997), severity of symptoms (Moh & Magiati, 2012), concurrent ADHD diagnosis (Eggleston et al., 2019) and age at diagnosis or detection (Bejarano-Martín et al., 2020; Goin-Kochel et al., 2006; Howlin & Moore, 1997) may also be associated with the level of satisfaction.

Although the characteristics of parents and children should always be considered in order to carefully support them throughout the process at an individual level, only the characteristics related to the experience of the process itself are likely to be modified and lead to recommendations at the national or regional level. This study focuses specifically on these process-related characteristics and uses data from the Autism Spectrum Disorder in the European Union (ASDEU 2015-2018) network to investigate the determinants of the level of satisfaction with the detection process. More specifically, the aims of this study were to 1) identify predictors of the level of satisfaction with the detection process and 2) to assess their relative importance to better understand their respective role

in explaining the level of satisfaction. From a public health perspective, knowing which predictors are more important than others can provide useful information to policy makers on which aspects of the process have the largest impact on the experience of the detection and should therefore be given priority.

## **Material and methods**

This study is a secondary analysis of data from an online multinational survey investigating the views and experiences of families and professionals about the services for early detection, diagnosis and intervention for autism across Europe. The survey was developed within the ASDEU network, a consortium of 20 partners, including universities, charities and expert institutions, from 14 European countries. The focus of this study is on the views and experiences of family members. A full description of the survey development and content, as well as recruitment procedures can be found in Bejarano-Martín et al. (2020). Only the essential characteristics are presented below.

### *Survey form development and content*

The content and items of the survey form were developed following focus-group sessions conducted with parents and professionals across 10 countries of the ASDEU network. Because each country has its own specificities in terms of health policies and health services, focus groups provided a standardized way to discuss topics related to early detection and diagnosis in each countries while ensuring that the content and items of the final survey form were contextually appropriate in most countries. A total of 37 questions were retained, covering socio-demographic characteristics, the detection and diagnostic processes and early intervention delivery. The final survey form consisted of both closed- and open-ended questions designed to ask parents about their experience, their opinion and their level of satisfaction relating to the services they had received (Supplementary Material 1). A pilot study, conducted in three countries (Spain, where the first

prototype of the survey form was developed, and two more countries, Denmark and Iceland, randomly selected from the ASDEU consortium), ensured that the questions were clear and understandable to parents. For the purpose of the present study, only questions pertaining to socio-demographic characteristics and the detection process were considered. The socio-demographic section included 11 questions covering child's characteristics, respondent's characteristics, and family conditions. The detection section included 10 questions covering the different steps of the process as well as the level of satisfaction with the process, the staff's qualifications and the degree to which professionals listened and took into account concerns. Finally, respondents were asked if they had any suggestions about the detection process.

#### *Recruitment procedure*

The survey form, initially developed in English, was formally translated into 13 country-specific versions before being uploaded to the Qualtrics web platform. The study was available online via the ASDEU project website ([www.asdeu.eu](http://www.asdeu.eu)). Respondents were recruited via parent associations and institutions that relayed the information about the study to their respective members and extended networks (e.g. through their website, social media site or bulletins). They were invited to read an information note about the study and had to sign an electronic consent prior to accessing the survey form. Ethical approvals were obtained in all countries.

#### *Data analysis*

##### Sample selection

To be included in the analyses, respondents had to 1) have completed at least the sociodemographic and detection sections of the survey and 2) reside in Europe. A total of 2,248 respondents initiated the study. Of these, 1,385 completed at least both the sociodemographic and detection sections of the survey. Among these respondents, 33 reported residency outside Europe

and were excluded. Therefore, analyses were performed on a sample of 1,352 respondents from 25 European countries (Table 1).

[Table 1]

### Variables Selection

To investigate determinants of satisfaction with the detection process, response to the question ‘*How adequate do you consider the detection process followed by the diagnostic evaluation?*’ was used as the outcome variable. Respondents assessed their level of satisfaction on a 7-point Likert scale.

Predictor variables of the level of satisfaction were selected a priori among the set of variables from the detection part of the survey. Only variables that 1) resulted from a close-ended question, 2) did not allow for multiple responses and, 3) were directly related to the detection process itself were considered. The final set of predictor variables included, the person who first raised concerns (hereafter, *concerns*), the ease of access to information about programs and early detection service (hereafter, *information*), the next step in the detection process (hereafter, *referral*), the time passed from the confirmation of the first concerns until the child was attended by an autism specialist (hereafter, *time*) and, professional guidance and support to address first concerns (hereafter, *guidance/support*).

### Statistical Analyses

Descriptive statistics were used first to quantitatively summarize the sample’s socio-demographic characteristics and detection process outcomes. Frequency, and proportion for categorical variables and mean, standard deviation, and interquartile range for continuous variables were used.

Since the outcome variable (satisfaction level) was ordinal, a proportional odds model was used to examine predictors of satisfaction. To best satisfy the ordinality assumption, the outcome variable was rearranged into a 3-level ordinal variable (unsatisfied (0) = *extremely inadequate* or *moderately inadequate*, neutral (1) = *slightly inadequate* or *neither adequate nor inadequate* or *slightly adequate*, satisfied (2) = *moderately adequate* or *extremely adequate*). However, unequal slopes were still allowed for the referral and time predictor variables since both variables violate the proportional odds assumption. Internal validity of the model was assessed with bootstrap resampling (B = 200) using concordance statistic (c-index) and Nagelkerke pseudo  $R^2$  as measures of discriminative ability and overall model performance respectively.

To further assess predictors' importance, a dominance analysis was performed following the procedure described in Azen & Traxel (2009). Dominance analysis allows to assess the relative importance of a predictor among a given set of predictors by determining its additional contribution to a model fit in all possible subset models. The additional contribution of a predictor is then compared to that of every other predictor in a pairwise fashion. For each pair of predictors, three levels of dominance were examined: complete dominance, when the additional contribution of one predictor is greater than that of the other predictor in all possible subset models; conditional dominance, when the average additional contribution of one predictor within each model size is greater than that of the other predictor; and general dominance, when the average conditional contribution is greater than that of the other predictor over all model sizes (Supplementary Material 2). Bootstrapping (B = 1000) was used as an inferential procedure as well as to evaluate the robustness of the results of the dominance analysis.

Additionally, sensitivity analyses were conducted using an alternative 3- and 5-level rearrangement of the outcome variable to assess the robustness of the findings to changes in the way the outcome variable is rearranged.

Missing values were present for the *concerns* predictor variable. Fraction of missing values was very low ( $< 0.01$ ,  $n=11$ ) and no distinctive pattern of missingness was detected. Single imputation, conditional on all other predictors, was used to fill-in missing values. Collinearity among predictor variables was not present as indicated by a redundancy analysis.

Data preparation, analysis and presentation were conducted in R (version 3.6.1; R Core Team 2019). Analysis code and output are provided in the R Markdown pdf file (Supplementary Material 3).

### *Community involvement*

Twelve parents, approached through several parents associations were consulted about the survey questions, format and response choices during a pilot study to ensure clarity and accessibility.

## **Results**

### *Sample characteristics and detection process outcomes*

The majority of respondents identified themselves as the mother or father of the autistic child (95%). The mean age of the respondent sample was 38.8 ( $SD = 7.1$ ) years and most of them were female (85%). The mean child's age at survey was 7.4 ( $SD = 3.8$ ) with a male to female ratio of 4.7. Sample's socio-demographic characteristics are described further in Table 2. The difference between the child's age at survey and age at diagnosis indicates that, on average, respondents completed the study 3.3 years ( $SD = 2.9$ ) after getting the diagnosis.

[Table 2]

Regarding the detection process (Table 3), the mean age at which someone first expressed concerns for a child was 28.8 ( $SD = 18.1$ ) months. Half of the respondents reported that the first concerns emerged between 16 to 37 months. Most often, the first person to express concerns was a family member of the child, either the respondents themselves (59%) or another member of the family (12%). Health professionals were involved in less than 1%. Sixty-eight percent felt it was not easy to access information on early detection programs and services and 51% reported that they had to look by themselves for a diagnostic service. In about 50% of cases, it took less than 6 months between the confirmation of the first concerns and the first consultation with an autism specialist. Fifty-three percent reported that they did not receive any professional guidance or support to address the first concerns. The mean age at diagnosis was 50.0 ( $SD = 24.0$ ) months, half of the diagnoses occurring between 33 and 63 months. Overall, 52% of the respondents expressed a positive level of satisfaction, by indicating that they judged the detection process either slightly adequate (12%), moderately adequate (23%) or extremely adequate (17%) and 36% expressed a negative level of satisfaction by responding that the detection process was either slightly inadequate (7%), moderately inadequate (10%) or extremely inadequate (19%).

[Table 3]

There were a total of 720 unique combinations of predictor levels, thus representing 720 possible different experiences; 343 unique combinations were actually observed in the sample with the most common combination occurring 119 times (8.9%). This combination was characterized by respondents reporting that they were the first to express concerns, that they had difficulty finding information about detection services, that they did not receive professional guidance and support in response to their initial concerns, that they had to find a diagnostic service on their own, and that there was a delay of more than 6 months between the confirmation of concerns and the first appointment with a specialist. The alluvial diagram in Figure 1 illustrates the variability in the detection process across respondents and how it relates to satisfaction levels.

[Figure 1]

### *Determinants of satisfaction*

Overall, the model was predictive of the level of satisfaction, LR  $\chi^2(21) = 416.1$ ,  $p < .001$ . The performance of the model after the validation procedure was adequate, with a discriminative overfitting-corrected c-index of 0.736 (apparent c-index, 0.741) and an overfitting-corrected Nagelkerke pseudo  $R^2$  of 0.256 (apparent Nagelkerke pseudo  $R^2$ , 0.301). Deviance table indicates that all predictor variables, except *concerns*, significantly predict the level of satisfaction after adjusting for the effects of all other predictor variables (Table 4).

Not receiving any professional guidance and support in response to initial concerns and difficulty finding information about early detection programs and services were two experiences associated with greater odds of being less satisfied. Likewise, a 3 to 4 months period or more between the confirmation of concerns and the first appointment with a professional were also associated with greater odds of being less satisfied compared to when a period of less than one month was experienced. Compared to when respondents had to find a diagnostic service by themselves, the odds of being less satisfied were lower when the professional contacted a diagnostic service, when respondents received a phone call or a letter for an appointment or when other actions were taken for referral. The adjusted associations (ORs and their 95% CIs) between individual predictors and satisfaction are provided in Table 4.

[Table 4]

Results of the dominance analysis are provided in Table 5 (see also Supplementary Material 2 Table 1). In general, results indicate that *guidance/support* is the most important predictor of the level of satisfaction because this predictor dominates all other predictors, albeit to different degrees of dominance. Reproducibility rates in bootstrapped samples indicate that a complete dominance is



well established over *concerns* (1.00) and that a more robust dominance is found at the conditional level over *referral* (0.90) and at the general level over *time* (0.80) and *information* (0.87).

Conversely, *concerns* was the least important predictor of the level of satisfaction because it was consistently completely dominated by all other predictors. In addition, a general dominance is established for *time* over *referral* and for *information* over *referral*, albeit at a lower confidence level. Finally, no clear pattern of dominance could be established between *time* and *information*.

[Table 5]

### *Sensitivity analyses*

The same analysis was performed again using an alternative 3-level and a 5-level rearrangements of the outcome variable (details in Supplementary Material 3). These alternative rearrangements featured both symmetry and balance with respect to a ‘neutral’ level of satisfaction, similarly to the original 7-level response scale. For the 3-level rearrangement, respondents who expressed a negative opinion (extremely, moderately or slightly inadequate) were grouped into a single level and those who expressed a positive opinion (slightly, moderately or extremely adequate) into another single level. For the 5-level rearrangement, respondents who expressed the two most extreme negative opinions (extremely or moderately inadequate) were grouped in a single level and those who expressed the two most extreme positive opinions (moderately or extremely adequate) into another level. These additional analyses reveal no substantial change in model performance and predictor significance from the primary analysis. Similarly, the dominance analyses are largely consistent with regard to the dominance pattern of *guidance/support* over all other predictors. Inconsistencies are noted for dominance patterns that have the lowest degree of confidence in the primary analysis. The general dominance of *time* over *referral* and *information* over *referral* is again established with the alternative 3-level rearrangement but not with the 5-level rearrangement. Likewise, a general dominance of time over information is found with the 3-level

alternative rearrangement, but not for the 5-level rearrangement with which no clear pattern of dominance between these two predictors is established, as for the primary analysis.

## **Discussion**

The aims of this study were to identify predictors of the level of satisfaction with the detection process of autism among a large multinational sample of family members of an autistic child ( $N = 1,342$ ) in Europe and to further investigate the relative importance of these predictors. Overall, respondents' experience with the detection process in the current sample was similar to that of other samples in the literature. With respect to the level of satisfaction, a relatively even distribution of the proportion of respondents across 7 ordered categories is observed. Although these results may be difficult to relate to previous reports because of different scaling options across studies, they highlight the variability in respondents' level of satisfaction with the detection process (Crane et al., 2016; Goin-Kochel et al., 2006; Höfer et al., 2019; Howlin & Moore, 1997; Makino et al., 2021). The extent to which this variability may be related to different experiences throughout the detection process is critical to establish. For example, parents who report high levels of dissatisfaction have likely encountered barriers or had negative experiences during their child's detection process. Identifying these barriers and negative experiences and knowing their relative importance to the level of satisfaction is an important prerequisite for guiding recommendations and ensuring that the detection process meets parents' expectations. The results of this study indicated that having had difficulty finding information about detection services, not having been guided and supported by professionals in response to first concerns, having had to find a diagnostic service on one's own and a delay of more than 4 months between the confirmation of concerns and the first appointment with a specialist, were all experiences individually associated with greater odds of being less satisfied.

The dominance analysis further revealed that professional guidance and support to address first concerns was the most important predictor of satisfaction. Understandably, as parents realize that something may be atypical with their child's development, their level of stress, uncertainty and anxiety increases dramatically, sometimes with an associated sense of personal guilt (DesChamps et al., 2020; Gentles et al., 2019). Many parents will eventually turn to a professional to share their concerns and seek validation or explanations about their child's development, especially if this is their first child. Some parents may also even already suspect autism at this stage (Caronna et al., 2007; Ryan & Salisbury, 2012). Minimizing or not addressing concerns may have devastating consequences for the course of the detection process as well as for the parent-professional relationships. Parents may wait for another appointment at a later date or seek another professional, resulting in increased delay in both cases (Smith-Young et al., 2020). Many parents reported feeling distressed and sometimes even humiliated when faced with a professional who minimizes or ignores their concerns (Boshoff et al., 2018). Instead, acknowledging parents' concerns, providing useful and accurate information about the child's development and what needs to be watched, and possibly referring the child to a diagnostic service, are effective strategies that can foster a positive parent-professional relationship (Caronna et al., 2007). A positive parent-professional relationship may help reduce parental stress and make parents more resilient to the system's shortcomings (Brogan & Knussen, 2003; Moh & Magiati, 2012). Moh and Magiati (2012) found lower levels of stress when parents reported efficient collaboration with professionals during the diagnostic evaluation and greater satisfaction towards the process (see also Crane et al., 2016). The quality of the parent-professional collaboration certainly plays a central role in parents' experience of the detection process, and it is perhaps not so surprising that professional guidance and support in response to first concerns was the most important predictor of the level of satisfaction. Autism guidelines and practice parameters usually recommend that any concerns raised by parents should be taken seriously by professionals (National Institute for Health and Care Excellence, 2011; Haute Autorité de Santé, 2018). However, some professionals concede that they may not be sufficiently

trained (Crais et al., 2014; Ghaderi & Watson, 2019; McCormack et al., 2020), and, like parents, often express a wish for better training (Locke et al., 2020; Osborne & Reed, 2008). The results of the present study indicate that improving the initial and ongoing training of professionals is a central element to be targeted and prioritized to foster a more satisfactory experience of the detection process. In practice, system-based programs to improve early detection usually include training sessions for professionals about early signs and existing screening tools (Broder Fingert et al., 2018; Daniels et al., 2014; García-Primo et al., 2014). However, beyond theoretical aspects on early detection, hands-on sessions to discuss and provide guidance about strategies for dealing with parental distress (Daniels et al., 2021), strategies for talking about autism concerns (Steinman et al., 2021), or strategies to foster shared-decision making (van Tongerloo et al., 2015) may ultimately do more to develop a stronger parent-professional partnership and build professionals' confidence in their ability to support and guide families.

Longer delays in the detection process are usually associated with lower satisfaction levels (Crane et al., 2016; Howlin & Moore, 1997). In this study, delay was operationalized as the time passed between the confirmation of concerns and the first appointment with a specialist. At this stage, parents may be faced with a heightened sense of urgency given the confirmation that their child is developing atypically and the need to begin intervention as soon as possible. The more time that passes during this period, the more likely parents will become increasingly frustrated and anxious (Gentles et al., 2019). A gradual increase in odds of being less satisfied with the detection process as the time went on was observed, with delays greater than 4 months being statistically associated with greater odds of being less satisfied. Accordingly, several guidelines recommend that the diagnostic assessment should start within 3 months of the referral to the autism specialists (e.g. Haute Autorité de Santé, 2018; National Institute for Health and Care Excellence, 2011). However, such timescales are difficult to meet in practice, the time between the confirmation of concerns and the first appointment with a specialist being highly dependent on the availability of diagnostic

services in the area (e.g. service congestion, length of waiting list). Ease of access to information on early detection programs and services as well as the referral modality for diagnostic services were also significant predictors of the level of satisfaction. Having had difficulty to find information and having had to find a diagnostic service on one's own are two experiences that can be considered as barriers in the detection process to access diagnostic services. Overall, these results are in line with the need expressed by parents for a smooth, consistent and standardized detection process, with better coordination between professionals and diagnostic services and with professionals more willing to make referrals (Locke et al., 2020; Osborne & Reed, 2008). Significant efforts should also be made to make information about detection services and pathways more accessible to parents, for example through posters or flyers in doctors' offices or childcare settings.

This study examined the relative importance of predictors of satisfaction, but the underlying reasons that lead some predictors to be more important than others remains to be explored. It is possible that the dominance of the guidance/support predictor over all other predictors simply reflects the fact that respondents perceive the professional's attitude in response to initial concerns as having had the most impact on the course of the detection process for their child. It is also important to acknowledge that the emphasis on process-related factors in this study should not obscure the potential role of other intermediate factors in the level of satisfaction with the detection process. For example, parental stress is likely to be one of these intermediate factors between process-related characteristics and the level of satisfaction. The dominance of professional guidance and support over all other predictors could also reflect the stronger influence this predictor may have on parents' stress levels. Another possibility is that professional guidance and support could have a broader influence on parents' emotional state than the other predictors, not only affecting stress levels but also parents' self-esteem and parents' sense of empowerment. Examining the complex dependency structure between process-related factors and parents' emotional reactions to them, and their influence on satisfaction levels, will be important for future studies.

*Strengths and Limitations*

This study relied on a relatively large sample of respondents. However, although respondents were recruited through various channels across countries (parents' associations, professional organizations, social networks), one cannot rule out that the sample would qualify as a convenience sample. First, respondents were not randomly selected and likely became aware of the study because of their connections to parent associations and professional organizations from which the study was disseminated. Although an effort was made to reach out to a maximum of parents outside of these networks (e.g. posting the link to the study on social networks), the sample might still be biased towards respondents belonging to these associations or organizations. However, it should be noted that being part of an association's network most likely has no influence on the experience of the detection process, which logically took place at a time when respondents were not yet members of those associations. Moreover, the even distribution of the levels of satisfaction ensures that the sample was not biased towards respondents expressing only a very positive or negative opinion. Second, only respondents with internet access were able to complete the study, limiting the participation of respondents with little or no internet access who are more likely to be from lower socio-economic backgrounds. Third, no data on ethnicity was collected in this study. Low-income and minority ethnic families often experience unique socio-cultural challenges in accessing and using health-care services and both, tend to be under-represented in surveys (Crane et al., 2016; Leeuw et al., 2020; Smith et al., 2020). Thus, the experience of the detection process and its impact on satisfaction for low-income and/or minority ethnic families is likely not well reflected in this study.

Another limitation is the retrospective design of the study. Although an average of only 3 years elapsed from the detection process to the time respondents completed the study, retrospective reports are prone to recall errors. In addition, the level of satisfaction at the time of the study may not reflect the level of satisfaction when parents just came out of the detection process years or

months earlier. However, it could be argued that respondents were able to make a more nuanced appraisal of their experience after having had the opportunity to retrospectively assess the pros and cons of the procedure and their experience with it over the longer term.

Finally, the sample included respondents from 25 European countries, each with its own specificities in terms of health policies and accessibility of health services. For example, a number of countries in this study have an established detection pathway for autism in place while others do not. Although we have ensured that the questions remain contextually appropriate for the different countries, the results cannot be interpreted with reference to any particular healthcare system. Rather they should be viewed as a global outline of the process-related factors that most influence the level of satisfaction with the detection process.

## **Conclusion**

In a previous study from the ASDEU network, Bejarano-Martín et al. (2020) showed that families' opinions were more negative compared to those of professionals regarding their satisfaction with the detection process and other services. In this study, we further explored parents' experience of the detection process and we investigated the determinants of satisfaction and their relative importance. Developing and ensuring that the autism detection process meets parents' expectations and guides them in a smooth and consistent manner towards their child's diagnosis is certainly not an easy task. Despite considerable efforts to enhance the detection process through the release of autism guidelines and practice parameters, barriers still exist. Professional guidance and support in response to first concerns was the most important predictor of the level of satisfaction with the process. Professionals play an important role in the detection process not only from an organizational perspective (i.e. being the first point of contact, making referrals), but also, and perhaps even more so, in the way they respond to parents' concerns.

## Reference

- Azen, R., & Traxel, N. (2009). Using dominance analysis to determine predictor importance in logistic regression. *Journal of Educational and Behavioral Statistics*, *34*(3), 319–347. <https://doi.org/10.3102/1076998609332754>
- Bejarano-Martín, Á., Canal-Bedia, R., Magán-Maganto, M., Fernández-Álvarez, C., Cilleros-Martín, M. V., Sánchez-Gómez, M. C., García-Primo, P., Rose-Sweeney, M., Boilson, A., Linertová, R., Roeyers, H., Van der Paelt, S., Schendel, D., Warberg, C., Cramer, S., Narzisi, A., Muratori, F., Scattoni, M. L., Moilanen, I., ... Posada de la Paz, M. (2020). Early Detection, Diagnosis and Intervention Services for Young Children with Autism Spectrum Disorder in the European Union (ASDEU): Family and Professional Perspectives. *Journal of Autism and Developmental Disorders*, *50*(9), 3380–3394. <https://doi.org/10.1007/s10803-019-04253-0>
- Bent, C. A., Barbaro, J., & Dissanayake, C. (2020). Parents' experiences of the service pathway to an autism diagnosis for their child: What predicts an early diagnosis in Australia? *Research in Developmental Disabilities*, *103*(June 2019), 103689. <https://doi.org/10.1016/j.ridd.2020.103689>
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. *Health & Social Care in the Community*, *October*, hsc.12691. <https://doi.org/10.1111/hsc.12691>
- Broder Fingert, S., Carter, A., Pierce, K., Stone, W. L., Wetherby, A., Scheldrick, C., Smith, C., Bacon, E., James, S. N., Ibañez, L., & Feinberg, E. (2018). Implementing systems-based innovations to improve access to early screening, diagnosis, and treatment services for children with autism spectrum disorder: An Autism Spectrum Disorder Pediatric, Early Detection, Engagement, and Services network study. *Autism*, 136236131876623. <https://doi.org/10.1177/1362361318766238>
- Brogan, C. A., & Knussen, C. (2003). The Disclosure of a Diagnosis of an Autistic Spectrum Disorder. *Autism*, *7*(1), 31–46. <https://doi.org/10.1177/1362361303007001004>
- Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language and Communication Disorders*, *51*(3), 328–338. <https://doi.org/10.1111/1460-6984.12210>
- Caronna, E. B., Augustyn, M., & Zuckerman, B. (2007). Revisiting Parental Concerns in the Age of Autism Spectrum Disorders. *Archives of Pediatrics & Adolescent Medicine*, *161*(4), 406. <https://doi.org/10.1001/archpedi.161.4.406>



- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism : The International Journal of Research and Practice*, *15*(1), 83–97. <https://doi.org/10.1177/1362361309354756>
- Crais, E. R., McComish, C. S., Humphreys, B. P., Watson, L. R., Baranek, G. T., Reznick, J. S., Christian, R. B., & Earls, M. (2014). Pediatric healthcare professionals' views on autism spectrum disorder screening at 12-18 months. *Journal of Autism and Developmental Disorders*, *44*(9), 2311–2328. <https://doi.org/10.1007/s10803-014-2101-2>
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153–162. <https://doi.org/10.1177/1362361315573636>
- Daniels, A., Halladay, A. K., Shih, A., Elder, L. M., & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: A systematic review of the literature. *Journal of the American Academy of Child and Adolescent Psychiatry*, *53*(2), 141–152. <https://doi.org/10.1016/j.jaac.2013.11.002>
- Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, *18*(5), 583–597. <https://doi.org/10.1177/1362361313480277>
- Daniels, N. F., Coughlan, B., & Duschinsky, R. (2021). How UK health care professionals conceptualise parental experiences of the diagnostic process for autism spectrum disorder: A qualitative study. *SAGE Open Medicine*, *9*, 205031212110313. <https://doi.org/10.1177/20503121211031310>
- DesChamps, T. D., Ibañez, L. V., Edmunds, S. R., Dick, C. C., & Stone, W. L. (2020). Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis. *Autism Research*, *13*(1), 82–92. <https://doi.org/10.1002/aur.2213>
- Eggleston, M. J. F., Thabrew, H., Frampton, C. M. A., Eggleston, K. H. F., & Hennig, S. C. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*, *62*, 18–25. <https://doi.org/10.1016/j.rasd.2019.02.004>
- Fuentes, J., Ferrari Arroyo, M. J., Boada Muñoz, L., Touriño Aguilera, E., Artigas Pallarés, J., Belinchón Carmona, M., Muñoz Yunta, J. A., Hervás Zúñiga, A., Canal Bedia, R., Hernández Rodríguez, J. M., Díez Cuervo, Á., Idiazábal Alecha, M. Á., Mulas Delgado, F., Palacios Antón, S., Tamarit Cuadrado, J., Martos Pérez, J., & Posada De la Paz, M. (2006). Guía de buena práctica para el tratamiento de los trastornos del espectro autista. *Revista de Neurología*, *43*(07), 425. <https://doi.org/10.33588/rn.4307.2005750>
- Fuentes, J., Hervás, A., & Howlin, P. (2020). ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment. *European Child and Adolescent Psychiatry*, *0123456789*. <https://doi.org/10.1007/s00787-020-01587-4>

- García-Primo, P., Hellendoorn, A., Charman, T., Roeyers, H., Dereu, M., Rogé, B., Baduel, S., Muratori, F., Narzisi, A., Van Daalen, E., Moilanen, I., de la Paz, M. P., & Canal-Bedia, R. (2014). Screening for autism spectrum disorders: state of the art in Europe. *European Child & Adolescent Psychiatry*. <https://doi.org/10.1007/s00787-014-0555-6>
- Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbin, K. A., & Szatmari, P. (2019). Coming to understand the child has autism: A process illustrating parents' evolving readiness for engaging in care. *Autism*, 136236131987464. <https://doi.org/10.1177/1362361319874647>
- Ghaderi, G., & Watson, S. L. (2019). "In Medical School, You Get Far More Training on Medical Stuff than Developmental Stuff": Perspectives on ASD from Ontario Physicians. *Journal of Autism and Developmental Disorders*, 49(2), 683–691. <https://doi.org/10.1007/s10803-018-3742-3>
- Gibbs, V., Aldridge, F., Sburlati, E., Chandler, F., Smith, K., & Cheng, L. (2019). Missed opportunities: An investigation of pathways to autism diagnosis in Australia. *Research in Autism Spectrum Disorders*, 57(April 2018), 55–62. <https://doi.org/10.1016/j.rasd.2018.10.007>
- Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism : The International Journal of Research and Practice*, 10(5), 439–451. <https://doi.org/10.1177/1362361306066601>
- Haute Autorité de Santé. (2018, February). Autism spectrum disorder: Warning signs, detection, diagnosis and assessment in children and adolescents – Clinical practice guidelines method. [https://www.has-sante.fr/upload/docs/application/pdf/2018-04/cpg\\_asd\\_diagnostic\\_assessment\\_child\\_teen-ager\\_2018.pdf](https://www.has-sante.fr/upload/docs/application/pdf/2018-04/cpg_asd_diagnostic_assessment_child_teen-ager_2018.pdf)
- Hidalgo, N. J., McIntyre, L. L., & McWhirter, E. H. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual and Developmental Disability*, 40(2), 147–155. <https://doi.org/10.3109/13668250.2014.994171>
- Höfer, J., Hoffmann, F., Kamp-Becker, I., Poustka, L., Roessner, V., Stroth, S., Wolff, N., & Bachmann, C. J. (2019). Pathways to a diagnosis of autism spectrum disorder in Germany: a survey of parents. *Child and Adolescent Psychiatry and Mental Health*, 13(1), 16. <https://doi.org/10.1186/s13034-019-0276-1>
- Howlin, P., & Moore, A. (1997). Diagnosis in Autism. *Autism*, 1(2), 135–162. <https://doi.org/10.1177/1362361397012003>
- Jones, E. J. H., Gliga, T., Bedford, R., Charman, T., & Johnson, M. H. (2014). Developmental pathways to autism: A review of prospective studies of infants at risk. *Neuroscience and Biobehavioral Reviews*, 39C, 1–33. <https://doi.org/10.1016/j.neubiorev.2013.12.001>
- Kasari, C., Freeman, S., & Paparella, T. (2006). Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. *Journal of Child Psychology and Psychiatry*, 47(6), 611–620. <https://doi.org/10.1111/j.1469-7610.2005.01567.x>

- Leeuw, A., Happé, F., & Hoekstra, R. A. (2020). A Conceptual Framework for Understanding the Cultural and Contextual Factors on Autism Across the Globe. *Autism Research*, 13(7), 1029–1050. <https://doi.org/10.1002/aur.2276>
- Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, 23(8), 1897–1910. <https://doi.org/10.1177/1362361319841488>
- Locke, J., Ibanez, L. V., Posner, E., Frederick, L., Carpentier, P., & Stone, W. L. (2020). Parent perceptions about communicating with providers regarding early autism concerns. *Pediatrics*, 145(April). <https://doi.org/10.1542/peds.2019-1895J>
- Makino, A., Hartman, L., King, G., Wong, P. Y., & Penner, M. (2021). Parent Experiences of Autism Spectrum Disorder Diagnosis: a Scoping Review. *Review Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s40489-021-00237-y>
- McCormack, G., Dillon, A. C., Healy, O., Walsh, C., & Lydon, S. (2020). Primary Care Physicians' Knowledge of Autism and Evidence-Based Interventions for Autism: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, 7(3), 226–241. <https://doi.org/10.1007/s40489-019-00189-4>
- Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 6(1), 293–303. <https://doi.org/10.1016/j.rasd.2011.05.011>
- National Institute for Health and Care Excellence. (2011, September). Autism spectrum disorder in under 19s: Recognition, referral and diagnosis. <https://www.nice.org.uk/guidance/cg128>
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3), 309–324. <https://doi.org/10.1177/1362361307089517>
- Oswald, D. P., Haworth, S. M., Mackenzie, B. K., & Willis, J. H. (2017). Parental Report of the Diagnostic Process and Outcome: ASD Compared with Other Developmental Disabilities. *Focus on Autism and Other Developmental Disabilities*, 32(2), 152–160. <https://doi.org/10.1177/1088357615587500>
- Ozonoff, S., Young, G. S., Landa, R. J., Brian, J., Bryson, S., Charman, T., Chawarska, K., Macari, S. L., Messinger, D., Stone, W. L., Zwaigenbaum, L., & Iosif, A.-M. (2015). Diagnostic stability in young children at risk for autism spectrum disorder: a baby siblings research consortium study. *Journal of Child Psychology and Psychiatry*, 56(9), 988–998. <https://doi.org/10.1111/jcpp.12421>
- Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Gammer, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slonims, V., McConachie, H., Howlin, P., Parr, J. R., Charman, T., & Green, J. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet*, 388(10059), 2501–2509. [https://doi.org/10.1016/S0140-6736\(16\)31229-6](https://doi.org/10.1016/S0140-6736(16)31229-6)

- Pierce, K., Gazestani, V. H., Bacon, E., Barnes, C. C., Cha, D., Nalabolu, S., Lopez, L., Moore, A., Pence-Stophaeros, S., & Courchesne, E. (2019). Evaluation of the Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months. *JAMA Pediatrics*, *173*(6), 578–587. <https://doi.org/10.1001/jamapediatrics.2019.0624>
- Rogers, S. J., Estes, A., Lord, C., Munson, J., Rocha, M., Winter, J., Greenon, J., Colombi, C., Dawson, G., Vismara, L. A., Sugar, C. A., Hellemann, G., Whelan, F., & Talbott, M. (2019). A Multisite Randomized Controlled Two-Phase Trial of the Early Start Denver Model Compared to Treatment as Usual. *Journal of the American Academy of Child & Adolescent Psychiatry*, *58*(9), 853–865. <https://doi.org/10.1016/j.jaac.2019.01.004>
- Ryan, S., & Salisbury, H. (2012). ‘You know what boys are like’: pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice*, *62*(598), e378–e383. <https://doi.org/10.3399/bjgp12X641500>
- Smith-Young, J., Chafe, R., & Audas, R. (2020). “Managing the Wait”: Parents’ Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed With Autism Spectrum Disorder. *Health Services Insights*, *13*, 117863292090214. <https://doi.org/10.1177/1178632920902141>
- Smith, K. A., Gehricke, J.-G., Iadarola, S., Wolfe, A., & Kuhlthau, K. A. (2020). Disparities in Service Use Among Children With Autism: A Systematic Review. *Pediatrics*, *145*(Supplement\_1), S35–S46. <https://doi.org/10.1542/peds.2019-1895G>
- Steinman, K. J., Stone, W. L., Ibañez, L. V., & Attar, S. M. (2021). Reducing Barriers to Autism Screening in Community Primary Care: A Pragmatic Trial Using Web-Based Screening. *Academic Pediatrics*, *000*, 1–8. <https://doi.org/10.1016/j.acap.2021.04.017>
- Thompson, A., & Suñol, R. (1995). Expectations as Determinants of Patient Satisfaction : Concepts , Theory and Evidence. *International Journal for Quality in Health Care*, *7*(2), 127–141. <https://doi.org/10.1093/intqhc/7.2.127>
- van Tongerloo, M. A. M. M., van Wijngaarden, P. J. M., van der Gaag, R. J., & Lagro-Janssen, A. L. M. (2015). Raising a child with an Autism Spectrum Disorder: “If this were a partner relationship, I would have quit ages ago.” *Family Practice*, *32*(1), 88–93. <https://doi.org/10.1093/fampra/cmu076>
- Wong, V., Yu, Y., Keyes, M. L., & McGrew, J. H. (2017). Pre-diagnostic and Diagnostic Stages of Autism Spectrum Disorder: A Parent Perspective. *Child Care in Practice*, *23*(2), 195–217. <https://doi.org/10.1080/13575279.2016.1199537>
- Zavaleta-Ramírez, P., Rosetti, M. F., Albores-Gallo, L., Vargas-Soberanis, M. A., López, O. N., & Medina-Mora, M. E. (2020). Pathways to a Diagnosis of Autism Spectrum Disorder. *Psychiatric Services*, *appi.ps.2019005*. <https://doi.org/10.1176/appi.ps.201900518>
- Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *Journal of Pediatrics*, *166*(6), 1431-1439.e1. <https://doi.org/10.1016/j.jpeds.2015.03.007>

- Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., Mailloux, Z., Smith Roley, S., Wagner, S., Fein, D., Pierce, K., Buie, T., Davis, P. A., Newschaffer, C., Robins, D., Wetherby, A., Stone, W. L., Yirmiya, N., Estes, A., ... Natowicz, M. R. (2015). Early Intervention for Children With Autism Spectrum Disorder Under 3 Years of Age: Recommendations for Practice and Research. *Pediatrics*, *136*(Supplement 1), S60–S81. <https://doi.org/10.1542/peds.2014-3667E>
- Zwaigenbaum, L., Bryson, S. E., Brian, J., Smith, I. M., Roberts, W., Szatmari, P., Roncadin, C., Garon, N., & Vaillancourt, T. (2016). Stability of diagnostic assessment for autism spectrum disorder between 18 and 36 months in a high-risk cohort. *Autism Research*, *9*(7), 790–800. <https://doi.org/10.1002/aur.1585>
- Zwaigenbaum, L., Bryson, S., & Garon, N. (2013). Early identification of autism spectrum disorders. *Behavioural Brain Research*, *251*, 133–146. <https://doi.org/10.1016/j.bbr.2013.04.004>

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**Table 1***Sample size by countries*

	Total N=1,342
	n (%)
Austria	23 (1.7)
Belgium	159 (11.8)
Denmark	94 (7.0)
Finland	51 (3.8)
France	104 (7.7)
Great Britain	18 (1.3)
Iceland	50 (3.7)
Ireland	79 (5.9)
Italy	86 (6.4)
Montenegro	18 (1.3)
Poland	221 (16.5)
Portugal	24 (1.8)
Romania	28 (2.1)
Russia	87 (6.5)
Spain	274 (20.4)
Other*	19 (1.4)

\*Other includes Croatia (n=1), Cyprus (n=1), Germany (n=5), Hungary (n=1), Lituania (n=1), Luxembourg (n=2), Malta (n=2), Norway (n=1), Slovenia (n=1) and The Netherlands (n=4).

Na (n=7)

**Table 2***Summary of the respondents sample's socio-demographics*

		Total (N = 1,342)
	n	
Age of respondents	1,334	38.8 (SD = 7.1; IQR = 34.0-43.0)
Gender	1,342	
• Male		200 (15%)
• Female		1,142 (85%)
Relationship with the child	1,342	
• Mother or Father		1,278 (95%)
• Grandparent		17 (1.3%)
• Sibling		8 (0.6%)
• Other		39 (3%)
Education level	1,339	
• Secondary		367 (27%)
• Tertiary		569 (43%)
• Vocational		403 (30%)
Child's age at the time of survey (years)	1,342	7.4 (SD = 3.8; IQR = 4.8-9.7)
Child's gender	1,342	
• Male		1,107 (83%)
• Female		235 (17%)
Child's language level at the time of survey	1,336	
• Does not talk		226 (17%)
• Single words only		180 (14%)
• Two- or three-words phrases		179 (13%)
• Sentences with four or more words		233 (17%)
• Complex sentences		518 (39%)

*Notes.* n = number of non missing data; Values expressed as frequencies and proportions (in parenthesis) for categorical variables and means, standard deviations and interquartile ranges (in parenthesis) for continuous variables.

**Table 3***Summary of the detection process outcomes*

		Total (N=1,342)
	n	
Age at first concerns (months)	1,342	28.8 (SD = 18.1; IQR = 16.0-37.0)
Person who first raised concerns	1,331	
• Respondent		783 (59%)
• Family member		166 (12%)
• Professional from public health service		68 (5%)
• Professional from private health service		24 (2%)
• Teacher or school staff		213 (16%)
• Other		77 (6%)
Ease of access to information	1,342	
• Yes		432 (32%)
• No		910 (68%)
Next step in the detection process	1,342	
• Ourselves had to look for a diagnostic service		685 (51%)
• Someone gave a phone call to refer us		45 (3%)
• We received a letter with a medical appointment		44 (3%)
• Professional who had the first concern refer us		325 (24%)
• Other		243 (18%)
Time passed	1,342	
• Less than one month		116 (9%)
• From 1 to 2 months		161 (12%)
• From 3 to 4 months		218 (16%)
• From 5 to 6 months		160 (12%)
• More than 6 months		430 (32%)
• Other		257 (19%)
Professional guidance and support	1,342	
• Yes		627 (47%)
• No		715 (53%)
Satisfaction with the detection process	1,342	
• Extremely adequate		226 (17%)
• Moderately adequate		311 (23%)
• Slightly adequate		164 (12%)
• Neither adequate nor inadequate		159 (12%)
• Slightly inadequate		96 (7%)
• Moderately inadequate		136 (10%)
• Extremely inadequate		250 (19%)
Age at diagnosis (months)	1,196	50.0 (SD = 24.0; IQR = 33.0-63.0)

*Notes.* n = number of non missing data; Values expressed as frequencies and proportions (in parenthesis) for categorical variables and means, standard deviations and interquartile ranges (in parenthesis) for continuous variables.



**Table 4***Wald statistics and coefficients (OR) for the partial proportional model*

Predictor	$\chi^2$	d.f.	<i>P</i>	Odds Ratio (95% Confidence Interval)
Person who first raised concerns (Concerns)	2.73	3	0.435	
<i>Reference level = Ourselves</i>				
• Health				1.04 (0.68-1.62)
• School				0.87 (0.65-1.17)
• Other				0.72 (0.45-1.15)
Ease of access to information (Information)	50.78	1	< 0.001	
<i>Reference level = Yes</i>				
• No				2.49 (1.93-3.20)
Next step in the detection process (Referral)	48.02	6	< 0.001	
<i>Reference level = Ourselves</i>				
• Phone/letter (unsatisfied vs. neutral or satisfied)				0.26 (0.13-0.52)
• Phone/letter (unsatisfied or neutral vs. satisfied)				0.61 (0.37-1.00)
• Professional (unsatisfied vs. neutral or satisfied)				0.45 (0.30-0.65)
• Professional (unsatisfied or neutral vs. satisfied)				0.46 (0.33-0.62)
• Other (unsatisfied vs. neutral or satisfied)				0.75 (0.53-1.07)
• Other (unsatisfied or neutral vs. satisfied)				0.53 (0.38-0.74)
Time passed (Time)	64.85	10	< 0.001	
<i>Reference level = &lt; 1 month</i>				
• 1 to 2 months (unsatisfied vs. neutral or satisfied)				1.46 (0.64-3.32)
• 1 to 2 months (unsatisfied or neutral vs. satisfied)				1.46 (0.85-2.51)
• 3 to 4 months (unsatisfied vs. neutral or satisfied)				2.08 (0.97-4.45)
• 3 to 4 months (unsatisfied or neutral vs. satisfied)				2.07 (1.25-3.44)
• 5 to 6 months (unsatisfied vs. neutral or satisfied)				2.77 (1.28-5.96)
• 5 to 6 months (unsatisfied or neutral vs. satisfied)				2.65 (1.54-4.56)
• > 6 months (unsatisfied vs. neutral or satisfied)				4.05 (2.01-8.16)
• > 6 months (unsatisfied or neutral vs. satisfied)				3.40 (2.11-5.47)
• Other (unsatisfied vs. neutral or satisfied)				5.08 (2.47-10.42)
• Other (unsatisfied or neutral vs. satisfied)				2.84 (1.70-4.75)
Professional guidance and support (Guidance/Support)	81.63	1	< 0.001	
<i>Reference level = Yes</i>				
• No				2.82 (2.24-3.53)

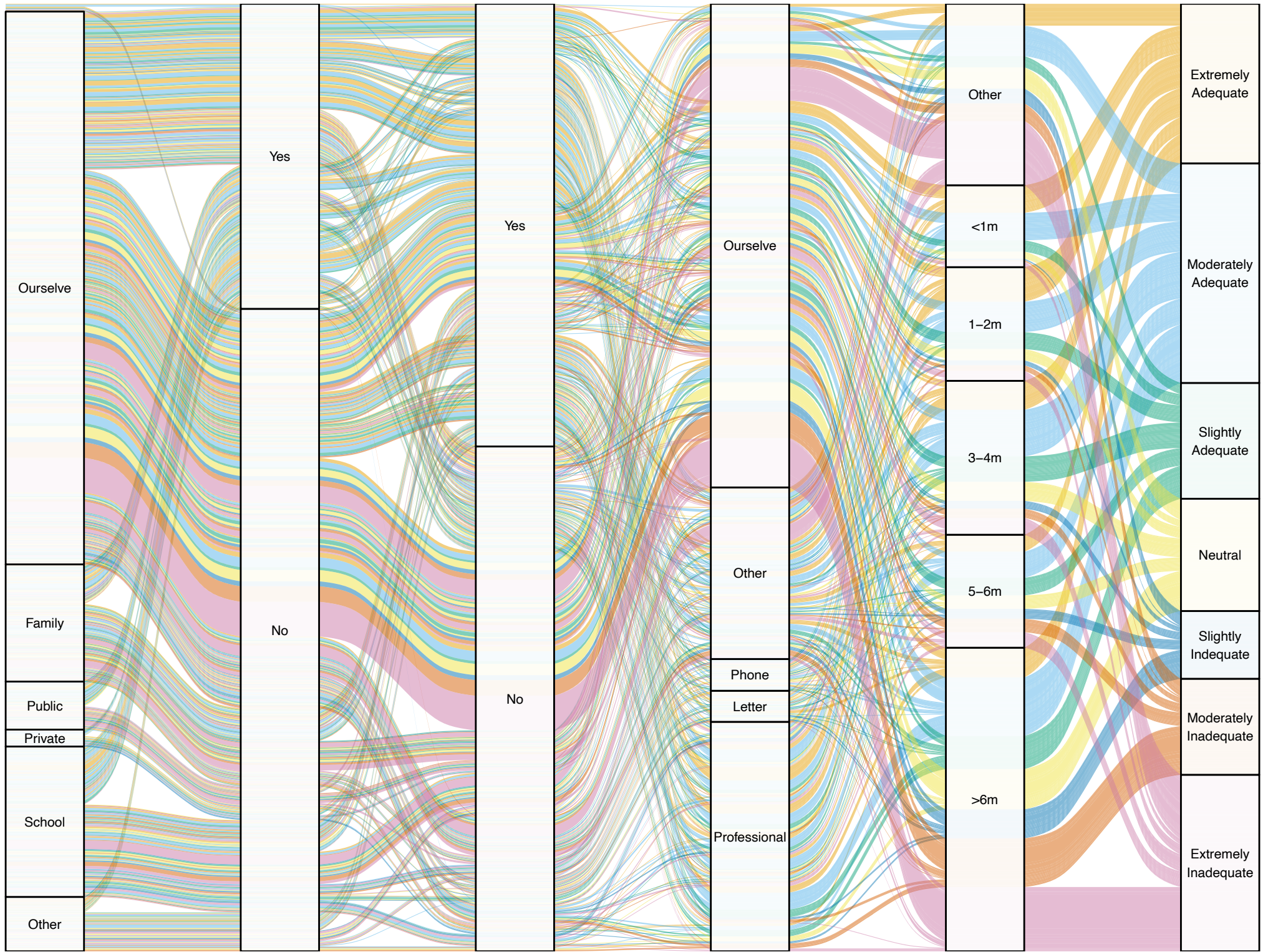
**Table 5***Results of the Dominance analysis*

i	j	Dij	mDij	SE.Dij	Pij	Pji	Pnoij	Rep
<i>Complete dominance</i>								
Guidance/Support	Concerns	1	1.000	0.000	1.00	0.00	0.00	1.00
Guidance/Support	Referral	1	0.866	0.007	0.74	0.00	0.26	0.74
Guidance/Support	Time	1	0.760	0.010	0.60	0.08	0.32	0.60
Guidance/Support	Information	1	0.819	0.008	0.66	0.03	0.31	0.66
Concerns	Referral	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Time	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Information	0	0.000	0.000	0.00	1.00	0.00	1.00
Referral	Time	0.5	0.284	0.009	0.03	0.46	0.52	0.52
Referral	Information	0.5	0.364	0.010	0.10	0.37	0.53	0.53
Time	Information	0.5	0.617	0.009	0.32	0.09	0.59	0.59
<i>Conditional dominance</i>								
Guidance/Support	Concerns	1	1.000	0.000	1.00	0.00	0.00	1.00
Guidance/Support	Referral	1	0.942	0.006	0.90	0.02	0.08	0.90
Guidance/Support	Time	1	0.764	0.010	0.61	0.08	0.31	0.61
Guidance/Support	Information	1	0.867	0.010	0.82	0.09	0.09	0.82
Concerns	Referral	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Time	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Information	0	0.000	0.000	0.00	1.00	0.00	1.00
Referral	Time	0	0.204	0.011	0.13	0.72	0.15	0.72
Referral	Information	0	0.356	0.011	0.14	0.42	0.44	0.42
Time	Information	0.5	0.615	0.011	0.37	0.14	0.49	0.49
<i>General dominance</i>								
Guidance/Support	Concerns	1	1.000	0.000	1.00	0.00	0.00	1.00
Guidance/Support	Referral	1	0.967	0.006	0.96	0.03	0.00	0.96
Guidance/Support	Time	1	0.807	0.012	0.80	0.19	0.01	0.80
Guidance/Support	Information	1	0.872	0.010	0.87	0.12	0.01	0.87
Concerns	Referral	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Time	0	0.000	0.000	0.00	1.00	0.00	1.00
Concerns	Information	0	0.000	0.000	0.00	1.00	0.00	1.00
Referral	Time	0	0.185	0.012	0.18	0.81	0.02	0.81
Referral	Information	0	0.308	0.014	0.30	0.68	0.02	0.68
Time	Information	0	0.627	0.015	0.62	0.36	0.02	0.36

Notes: Dij = original result (dominance i over j = 1; dominance j over i = 0; no dominance = 0.5); mDij = mean for Dij on bootstrap samples (N=1000); SE.Dij = standard error for Dij on bootstrap samples; Pij = proportion of bootstrap samples where i dominates j; Pji = proportion of bootstrap samples where j dominates i; Pnoij= proportion of bootstrap samples where no dominance could be asserted; Rep = proportion of sample where original dominance is replicated.

**Figure captions**

**Figure 1.** Alluvial diagram of the detection process. The figure shows six vertical axes representing the 5 predictor variables and the outcome variable, as well as the observed proportion of the different response options for each variable (strata). The horizontal splines connecting the different axes to specific strata correspond to unique combinations of responses for the five predictors and the outcome variable, colored according to the corresponding satisfaction level. The width of the splines is proportional to the number of times the combination was observed. Note that because the same combination of response across the five predictors can result in different level of satisfaction, the figure has 739 unique combinations.



Concerns

Information

Guidance/Support

Referral

Time

Satisfaction