



# Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

## Work Package 2:

Report on requirements and models for supporting children with complex mental health needs at the primary and secondary care interface.

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# **Report on requirements and models for supporting children with complex mental health needs and the primary care interface.**

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## Executive Summary

### Background

The MOCHA project (Models of Child Health Appraised) is a multidisciplinary study of primary healthcare seeking to describe the current child healthcare models that exist in all 30 EU/EEA countries. This report provides a comprehensive analysis of the current approach to managing the care of children with complex mental health care needs at the interface of primary care. Children with complex mental care needs are defined as those with substantial care needs resulting from one or more conditions, which require access to multiple health and social support services. These needs can be best fulfilled when their care is integrated so that children and their families receive a continuum of preventive and curative services according to their needs over time and across different levels of the health system. Thus, in addition to describing the approach to managing the care of children with enduring complex mental health care needs, the aim of this study was also to identify facilitators and barriers to achieving a continuum of care at the interface of primary care.

### Methods

Autism Spectrum Disorder (ASD) and ADHD were selected as tracer mental health conditions, as they are characterized by their persistent complex care needs across the specialized and general psychiatric, medical and social services. The main part of this task consists of a mixed-methods study of 30 European countries to collect survey data and qualitative commentary from key informants in each country. The questionnaire was composed of patient vignettes and the adapted *Standards for Systems of Care for Children and Youth with Special Health Care Needs and Complex Care European Survey of Change*. A thematic analysis of the qualitative responses was conducted to identify basic, organising and global themes that influence the interface of primary care.

This study also incorporates other strands of the MOCHA project, namely, a qualitative exploration of patient and family experiences (DIPEX International), business process models of actors involved in complex care, and a mixed-methods study conducted by Murdoch Children's Research Institute in Australia. The range of methods and perspectives used adds to the understanding of the complex and multi-faceted topic of care for complex mental health conditions.

### Key principles

From the multiple perspectives gained as strands of this study, key principles influencing complex care for children with enduring mental health needs were derived, under three main themes:

#### Access

- On-going screening and developmental checks should be provided regardless of detected mental health conditions
- Care provision should be accessible regardless of the geographic location of the child and family
- Care services supporting children with mental health condition should be in place in both primary, secondary and social care
- Access to care should follow a stepped care approach

- Consideration should be given to regional differences
- Care pathways are in place to support care delivery at the interface between services
- Fee-based care proved to be a barrier in accessing care, in particular for low-income families
- Transparent referral procedures support continuity of care
- Attention to transitions between services and/or as children grow up are a part of the personal care plan of every child with mental health conditions
- Political awareness and collaboration should facilitate guidelines that enhance simultaneous access to different services

### **Parental involvement**

- Parents should be included as partners in their child's care
- Parents should receive information about their child's care in a linguistically and culturally appropriate manner
- The families of children with mental health conditions are provided with psychosocial support
- Parents and parent advocacy groups are invited to participate in the development of policies and procedures affecting their child
- Parents should be provided with an overview of their child's caregivers
- Parents should be presented with an overview of possible accessible care services and their interfaces
- Parents should have a voice in quality assurance at regional and national level

### **Multidisciplinary teams**

- The required level of knowledge about both health care and social care for mental health conditions should be ensured
- Responsibilities between caregivers should be communicated and coordinated
- A personalized care plan should be accessible for all involved professionals across sectors and across services
- The results of screening and assessment should be accessible for all caregivers
- Professionals across sectors should be included as partners in regional and national quality assurance
- A standard for the multidisciplinary approach in care provision for children with mental health conditions could heighten coordination between health care and social care
- Primary care providers have specialised training in the care of children with mental health conditions
- Social care providers have specialised training in the care of children with mental health conditions
- The ranges of care services have training in how to coordinate care
- School health systems have specialised training and are able to support and educate the child with mental health conditions

## **SECTION A:**

# **Systems of care for children with complex mental health conditions in Europe (using ADHD and Autism as exemplars)**

## **1. Introduction**

The MOCHA project (Models of Child Health Appraised) is a multidisciplinary study of primary healthcare seeking to describe the current child healthcare models that exist in all 30 EU/EEA countries. The aim of this task is to provide an updated comprehensive analysis of the current approach to managing the care of children with complex mental health care needs at the interface of primary care.

This report presents an analysis of the current approach to managing the complex care needs of children with enduring mental health conditions at the primary/secondary interface. The main part of the study examined complex care in 30 European countries and data was collected using MOCHA Country Agents. This also involved the development of a glossary of relevant terms and the selection and adaptation of existing measures to explore the integration of care for children with complex care needs. Vignettes depicting an example patient for each condition were developed to provide context for Country Agents responding to the survey.

This report also incorporates insights from multiple strands of the MOCHA project, as the work of the European mental health team was complemented by contributions from the DIPEX International regarding the patient and family experience, business process models of actors involved in complex care, and a national study with comparable methodology conducted by Murdoch Children's Research Institute in Australia (which is described in Section B).

Section A of this report describes the work of the European MOCHA teams. Chapter 1 outlines the background to this area of the MOCHA project and the aims and objectives of our task. Chapter 2 presents the methods used to gather and analyse the data to date. The findings on the integration of care for children with Autism Spectrum Disorder (ASD) and Attention Deficit/Hyperactivity Disorder (ADHD) are presented in Chapters 3 and 4 respectively, with insights on the patient experience and a business process model approach to actors involved. Chapter 5 reflects on the methodological approach and limitations of the approach used.

Section C presents the triangulated findings from ADHD and ASD, first examining the convergence on European and Australian findings and then comparing results from ADHD and ASD. The final chapter discusses the needs and future visions for care of children with complex mental health conditions, highlighting the key principles for supporting children with enduring mental health needs at the interface of primary care.

### **1.1. Enduring Mental Health Conditions and Integration of Care**

The United Nations Convention on the Rights of the Child (to which all European Union (EU) and European Economic Area (EEA) Member States are signatories) defines the highest attainable standard of healthcare as a fundamental right of every child [1]. The extent to which this requirement is met in practice by national healthcare systems varies considerably among

the countries of Europe, and is the core purpose of the Horizon 2020-funded project, Models of Child Health Appraised (MOCHA). One aspect of the MOCHA project is to provide an up-to-date comprehensive analysis of the current approach across 30 European countries to the management of care for children with complex care needs, with particular regard to the integration of care at the acute/community/primary interface. Integrated care refers to the management and delivery of health services so that children and their families receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system [2].

The World Health Organization (WHO) states that globally 10-20% of children and adolescents experience mental disorders [3], half of which continue into adulthood [4], and neuropsychiatric conditions are the leading cause of disability in young people [5]. If these conditions are not managed, they will strongly influence the child's development, educational attainments and potential to live a fulfilling life [6]. There is thus a need for an increased focus on meeting care needs regarding child and adolescent mental health (CAMH), not only to ensure children and young people's present well-being and development, but also to prevent negative consequences in the future.

Children with complex care needs are defined as those with substantial care needs resulting from one or more congenital, acquired or chronic conditions, which require access to multiple health and social support services [7]. For children and adolescents with mental health issues, the interface between primary and secondary care systems is crucial because the care needs are often detected and treated in the educational or social care systems [8]. Thus, primary and secondary services caring for CAMH often fall under the jurisdiction of ministries other than health. Transitions at the point of interface can pose risks to the quality, appropriateness and timeliness of care and indeed the safety of the child.

## 1.2. Complex care needs for children with ADHD and ASD

This study will examine the integration of care for two mental health diagnoses, ADHD and ASD, which were selected as exemplar mental health conditions, as they present complex care needs<sup>1</sup>. Both are characterized by their persistence and requiring a high level of effective integration between specialized and general psychiatric, medical and social services. The focus on two tracer conditions facilitates more specific and concrete data to be collected, and nuances regarding the real-world care of these conditions to be drawn out.

Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) have an estimated prevalence of approximately 1% and 5% respectively [9, 10, 11, 12, 13]. Neurodevelopmental disorders are characterized by profound heterogeneity, and the level of

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<sup>1</sup> It is worth noting that this study examines the interface between primary and secondary care of children with autism and ADHD, rather than the diagnosis of these conditions. For this reason, the distinction between the diagnostic criteria defined in the International Classification of Diseases (ICD-10) [45] and Statistical Manual of Mental Disorders (DSM-IV) [46] will not be discussed further, despite being an important area of debate.

functional impairment caused by the diagnoses varies from mild to severe and can heavily impact the individuals with ASD or ADHD and their families. ASD and ADHD are complex psychological and medical conditions associated with a high degree of psychiatric comorbidity [14, 15, 16, 17].

ASD can be defined as a set of heterogeneous neurodevelopmental conditions, characterised by early-onset difficulties in social communication and unusually restricted, repetitive behaviour and interests [9]. Treatment of ASD aims to improve and maximise an individual's functional independence and quality of life through development and learning, improvements in social skills and communication, reductions in disability and comorbidity, promotion of independence, and provision of support to families. The most effective interventions have proven to be behavioural and educational; pharmaceutical treatment has yet only played a minor role and mostly in relation to comorbid diagnoses.

ADHD is a childhood-onset neurodevelopmental disorder characterised by developmentally inappropriate and impairing inattention, motor hyperactivity, and impulsivity, with difficulties often continuing into adulthood [18]. Between the ages of four and six, ADHD is the most common disorder including hyperkinetic disorder and conduct disorders. A stepwise approach to treatment is recommended, beginning with non-drug interventions and then progressing to pharmacological treatment in those most severely affected. Non-pharmaceutical aspects of the care of ADHD may involve multiple health and social support services and thus ADHD, like ASD, should be considered as requiring complex care.

Therefore, the needs of children with ASD or ADHD are typically multifaceted as they may need pharmacological, educational, psychotherapeutic, social and economic support requiring a range of different specialized units and professionals. For instance, medication can seldom be seen as a stand-alone treatment since children with ADHD who have been receiving medication still have worse educational and health outcomes than their peers [19]. Despite of the importance of integration between health care and social care, including community-based services, children with ASD and ADHD often experience fragmented care [20, 21]. Meeting all care needs requires continuity across the range of services [22], but integrating care has generally proven to be challenging and complex [23]. This study aims to investigate the interface of care for children with ASD and ADHD with particular attention to the facilitators and barriers of care integration.

## 2. Methods

This chapter provides a brief overview of the methods used by the European mental health team, DIPEX and the business model team. ASD and ADHD were selected as exemplar mental health conditions, as they are characterized by their persistent complex care needs across the specialized and general psychiatric, medical and social services. The DIPEX study concentrated on ADHD.

A detailed description of the data collection methods used by the European mental health team can be found in the report of Task 2, Work Package 2 (D2.8) [24] and the journal article published in the *International Journal of Integrated Care* [25].

### 2.1. Meso-level interface of care (European team)

The international character of the MOCHA project demanded an approach that could facilitate data collection in 30 countries and produce an element of international comparison. A descriptive, mixed-methods approach was therefore used, collecting categorical and qualitative data via a survey. The questionnaire specific to WP2 Task 3 consisted of three parts;

1. Vignette
2. Questionnaire adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (CYSCHN) [26]
3. Questionnaire based on the *Complex Care European Survey of Change*, adapted from the *Eurobarometer Survey* [27]

#### 2.1.1. Vignette development

A vignette for each condition accompanied the questionnaire to provide context and real-world examples to orient the respondent. Guided by best practice in writing vignettes [28], the research team drew on their clinical expertise and literature on studies of the coordination and integration of care for children with complex health needs. The vignettes were designed to provide clinically-relevant detail regarding the patient, setting, problem and context and yet avoid overburdening the respondent with superfluous information [29]. The vignettes for ASD and ADHD are presented below:

*Marcus is 2 years and 5 months old and has been newly diagnosed with autism. His development was considered normal up to the age of 15 months. He communicated with babble, held eye contact and reached motor skill milestones as expected. At 18 months Marcus's development began to stagnate, he experienced language regression and had difficulty maintaining eye contact. His parents described him as socially withdrawn, lacking interest in interacting with peers and having mannerisms with his hands. He also has a tendency to run askew, with his hands turned backwards. Currently, at diagnosis, Marcus has been assessed as having severe and pervasive difficulties in all areas of the autistic spectrum. He is not developing age appropriate expressive or receptive language. In addition, his ability for social interaction as well as functional and symbolic play is found to be deviant and not age appropriate. This is considered stereotypical of autism. Marcus's gross and fine motor skills are also affected.*

*His future health and social care should be delivered in an environment where specialists with expertise in respect to autism can provide a care plan to support his development. It is also advised that his parents receive guidance in meeting Marcus's needs in the family setting. Marcus's condition is irreversible and he is expected to receive lifelong care and treatment, aimed at preventing further regression and develop new skills. The care will be provided by a multi-disciplinary team consisting of psychiatrists, psychologists, physiotherapists, occupational therapists, special community child and youth workers, social care workers, home care nurses and respite care services.*

#### *2.1.1a: Vignette for ASD*

*Pedro is a 12 year old boy. Since his parents divorced two years ago he now lives with his mother and her new husband, his 14 year old sister and his two older stepsisters. He was diagnosed with ADHD at the age of 8. Prior to Pedro's diagnosis he found it hard to concentrate in school and was restless and disruptive in class. At home he also displayed challenging behaviour and had sleep issues. Currently he is being treated with medication and his family has received instructions on how best to support him by introducing structured daily routines. His sleeping issues are being treated with a special weighted blanket and a sleep hormone with good effect. Pedro's medical treatment is followed up on a regular basis by a specialist. He attends the local mainstream primary school. Since starting treatment Pedro's concentration in school has increased but he still struggles with his school work. In order to minimise Pedro's specific academic challenges, he has been given his own workstation in the classroom and his teachers have been advised to structure his school day. In addition, his teacher has been asked to ensure that before starting a new task Pedro is listening and understands the task. These accommodations should assist Pedro's concentration and enable him to better complete his school work.*

#### *2.1.1b: Vignette for ADHD*

### **2.1.2. Systems of Care for Children and Youth with Special Health Care Needs (CYSCHN)**

Following an extensive review of the literature and potential instruments, the *Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSCHN)* was selected as the most suitable due to its broader focus on the integration of care of children with complex care needs at the acute/community/primary interface, rather than care coordination specifically. The standards were developed by the Lucile-Packard Foundation and examine the core components of the structure and process of an effective system of care to meet complex care needs. These standards were originally developed in the United States using literature, stakeholder experiences and case studies of existing standards, and were adapted for a European context. The sub-sections are as follows: screening, assessment and referral; access to

care; care coordination; community-based services and supports; family-professional partnerships; transitioning from paediatric to adult healthcare services; and quality assurance.

### 2.1.3. Complex Care European Survey of Change

The third part of the survey focussed on the wider context of healthcare policy and socio-cultural factors using the adapted *Complex Care European Survey of Change* [27]. This section of the questionnaire invited each Country Agent to provide a commentary on how they evaluated their country's progress with regard to meeting the integrated care needs of children with ASD and ADHD. This aimed to provide a "snapshot" of the current situation of integration of care for children with complex care needs. The Country Agents were asked to identify relevant socio-cultural factors, such as key facilitators and barriers, public awareness and political engagement, to help gain an understanding of the current issues and debates on the issues of complex care for children with ASD and ADHD in each country in the last five years.

### 2.1.4. Data collection

A key methodological feature of the MOCHA project was the delegation of data collection to a Country Agent in each of the participating states. Country Agents were recruited as local experts in child health services to take responsibility for data collection in their country by acting as informants to source the information requested by MOCHA researchers via questionnaires.

Since the official language of the MOCHA project is English, Country Agents proficient in scientific English as well as their local language(s) were selected to circumvent the need for extensive translation. To ensure consistency, clarity and accuracy in the use of terminology, a glossary of relevant terms was provided with the survey to aid interpretation of Country Agents and informants (see Figure 2.1). This was part of an overall glossary of terms for the MOCHA project and for Work Package 2, which have been made available on the project website and developed for use with Country Agents using international legislation and literature.

*To ensure alignment in translation across the EU countries, some of the questionnaire keywords are specified here:*

***Process:*** A set of interrelated activities, which transform inputs into outputs.

***Procedure/guideline:*** Description of actions done in a certain way.

***Policy:*** A plan or course of action, as of decision makers at macro and meso-level intend to influence and determine decisions, actions, and other matters. This is refers to a legal framework.

***System:*** A set of methods, procedures, arrangements, and activities that are carried out to form a unity or to meet a common goal.

Figure 2.1: Glossary accompanying the questionnaires

In order to obtain detailed and accurate data, the Country Agents were given the opportunity to clarify their answers as requested by research team, who asked for clarifications in cases when responses:

- seemed contradictory or divergent;
- indicated that the respondent was unsure of the answer or question;
- were provided in a language other than English;
- were missing.

At the end of the project, Country Agents were given the opportunity to review the draft report to ensure that the integration of care in their country was accurately represented.

### **2.1.5. Response rate**

Of the 30 countries participating in the MOCHA project, 25 responded to the ADHD questionnaire (83.3%) and 26 responded regarding ASD (87%) in the advised timeframe (see *Appendix 2*) except one country answered the majority of the categorical Standards for CYSCHN section of the questionnaire. One country (Sweden) felt that the format of questions and the case scenario presented did not fully represent the experience of care in their country and so provided a narrative description as opposed to completion of the questions posed. A minority of respondents did not provide extensive qualitative commentary, but most gave their perspectives on complex care in their countries. Responses that were received after August 2017 are not included in the current analysis.

### **2.1.6. Methods of Analysis**

The categorical data collected by the European Country Agents were analysed using descriptive statistics with frequencies and distribution by country presented in the following chapters. Qualitative analysis of the text commentary was subject to thematic analysis and presented as networks, “web-like illustrations that summarize the main themes constituting a piece of text” [30]. Initially, the lowest level of extraction formed Basic Themes, which were then arranged under Organising Themes and finally summarised as Global Themes. Presentation of themes as networks illustrates the relationships underlying the text and aids interpretation of the key factors for integration of care for children with ADHD and ASD. While the survey covered the seven domains of the Lucile-Packard framework separately, the content of the comments crossed over multiple domains and were thus pooled and analysed collectively.

## **2.2. Study of patient and family experiences (DIPEX)**

The DIPEX study focused on experiences of primary care of “healthy” children and those with complex physical and mental health conditions (including ADHD) and their parents, using the qualitative research methodology developed by the Health Experiences Research Group (HERG) University of Oxford [31]. Five European countries took part in the DIPEX study, which sits within the wider work of Work Package 1 (Identification of models of children’s primary healthcare) and Work Package 2 (Interface with secondary, social and complex care). In total, 84 children participated in the study, of which 29 children had ADHD and some had comorbidities. In addition, 88 parents took part in the study, of which 30 had a child with ADHD or another enduring mental health condition.

Illness narratives and unstructured, open-ended interviews and focus groups were conducted with children and parents in order to identify participants’ concerns, meanings and priorities rather than being restricted by the research interests. A qualitative interpretative approach to

analysis was taken, combining thematic analysis with constant comparison. A full description of the methods used by the DIPEX study can be found in the deliverable for *WP1 Report on Patient Experiences of Primary Care in 5 DIPEX countries* [32] and an appendix to *WP2 D2.4 Report on needs and future visions for care of children with complex conditions* [33].

Country	Participants			Age range	Diagnosis
	All	Female	Male		
Czech Republic	4	1	3	12-16	4 ADHD only
Germany (secondary analysis)	14	4	10	14-18	1 ADHD and depression, 1 ADHD, depression and suicidal thoughts, 2 ADHD only
Netherlands	3	1	2	10-11	1 ADD, 2 ADHD
Spain	4	1	3	10-15	4 ADHD only
UK	4	2	2	14-15	1 ADHD, epilepsy and asthma, 1 ADHD and epilepsy, 1 ADHD with suspected bipolar, 1 ADHD only

Figure 2.2: Child participants in the DIPEX study

Country	Participants			Age range	Number of children	Age range of children
	All	Female	Male			
Czech Republic	4	4	0		1-2+1	5-33
Germany (secondary analysis)	9	7	2	32-53	1-6, 3 unknown	Unknown
Netherlands	5	5	0	33-48	1-3	1-23
Spain	7	6	1	32-50	1-4	10-15
UK	5	4	1	38-51	2-3	10-18

Figure 2.3: Parent participants in the DIPEX study

### 2.3. Development of business process models (CNR)

Data collected using the *Lucile Packard Standards for Systems of Care for CYSCHN* survey was used to develop business process models of key processes involved in the complex care of children with ADHD and ASD. The analysis focussed on the questions reporting the types of professionals performing different actions and the level of collaboration among the different professionals in order to identify the actors who:

- provide health and social care preventive screening and developmental checks;
- develop and implement the written personalized plan.

For each activity, information on whether professionals work as a team or as individual practitioners performing specific professional-related activities was gathered. Moreover, some narratives allowed us to identify countries where the above-mentioned activities are carried out by a multidisciplinary team composed of professionals belonging to health and social care and generally co-located in a specific facility. Starting from this information the following levels of collaboration have been identified and classified:

1. *Professional collaboration*: a multidisciplinary team composed of primary care, mental health and social care professionals, and sometimes school care professionals.

2. *Mixed team*: a) mental health professionals and social professionals, e.g. social worker, counsellors, or b) primary care physicians and social care workers.
3. *Primary and secondary care team*: primary care physicians (e.g. GP, paediatrician) and specialists in mental health (e.g. psychiatrist, psychologist).
4. *Care team*: professionals belonging to the same setting- a) primary care professionals, b) mental health professionals, or c) social professionals.
5. *Individual professionals*: either health or social care providers not working in a team.

For each activity (represented by an ellipse), a UML use case diagram was developed that describes the professionals involved and highlights their level of collaboration using the UML composition symbol  $\text{---}\diamond$ . For instance, an example of Professional Collaboration is shown in Figure 2.4a, where the PC & SC & SoC Team is composed of PC (Primary Care), SC (Secondary Care) and SoC (Social Care) professionals.

The diagram also provides green notes (see Figure 2.4b) that report the types of actors involved in the related activity for each country, as highlighted by the dotted lines.

Results were summarised in maps, with countries that did not answer the specific question or that did not return a questionnaire (Luxembourg, Sweden, Slovenia and Slovakia) both marked in dark grey.

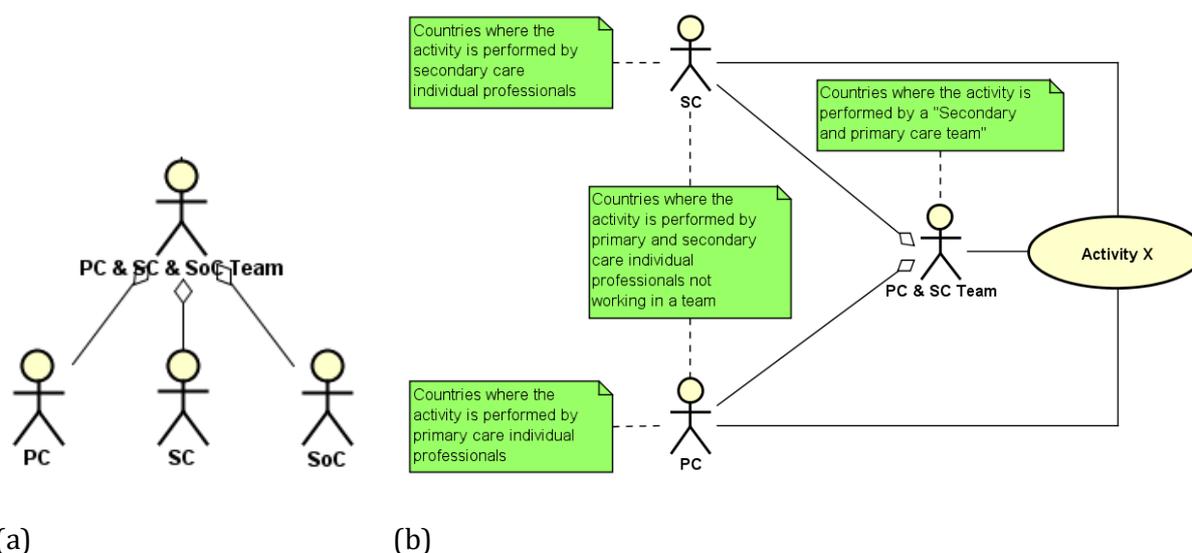


Figure 2.4: Example of a professional collaboration where a PC & SC & SoC Team is a composition of PC (Primary Care), SC (Secondary Care) and SoC (Social Care) professionals.

## 2.4. Integration of findings

This report contains insights from multiple strands of the MOCHA project, namely DIPEX patient experiences, a business process model approach and the parallel qualitative Australian study. The multi-faceted nature of complex mental health conditions requires that a broad range of methodologies be employed to triangulate findings.

The results from these pieces of research were integrated into the findings from the European mental health study to form cohesive conclusions. A convergence approach [34] to the DIPEX work was taken, using main themes from DIPEX to complement and illustrate the ADHD

findings from the mental health team. Business models of critical processes based on the Standards for CYSCHN questionnaire were developed by the *Consiglio Nazionale delle Ricerche* team. These diagrams clarify the organisation of complex care services across Europe, adding explanatory power to the analysis of the mental health team. The categorical and qualitative responses to the *Standards for Systems of Care for CYSCHN*, answers from the *European Survey of Change*, and the business process models developed by CNR, as well as the insights from DIPEX patient experience study for ADHD, were combined and organised thematically to present a synthesis of findings for the care of each condition in Europe.

In Section C of this report, the findings from Europe and Australia were examined using convergence matrices [34] to highlight similarities and differences between the two regions as expressed by respondents, followed by a comparison of findings relating to ADHD and ASD to bring out the discrepancies in care for the two conditions and what can be learned to inform the treatment of other enduring mental health conditions.

### 3. Findings: The Interface of Care for Children with ASD

This chapter reports on the results obtained to date on the integration of care for children on the autistic spectrum across MOCHA study countries. Responses from 26 of 30 (86.7%) of the MOCHA study countries have been returned (*Appendix 2*). The categorical results from the *Standards for Systems of Care for CYSCHN* are presented first, followed by business models representing key aspects of care for children with ASD. Facilitators and barriers of integrated care arising from the qualitative commentary of the *Standards* and the *Survey of Change* are then described, before a synthesis of the above findings is presented.

#### 3.1. Structures and processes of care in place for a child with ASD

The results from the categorical questions of the *Standards for Systems of Care for CYSCHN* are arranged by sub-section.

##### 3.1.1. Screening, assessment and referral

Respondents were asked about screening, assessment, referral and follow-up for children with and without potential indications of ASD.

##### 3.1.1.1. Policies and procedures for ongoing preventative care, screening and developmental checks

Of the 26 countries that responded, more than half (n=14) reported having both policies and procedures in place to assure that a child on the autistic spectrum receives ongoing preventative care screening and developmental checks with regards to their ASD diagnosis. Four countries reported having either a policy or a procedure and eight reported having neither. For four countries, the policies or procedures referred to were not specified, and in Finland, a comprehensive care guideline with a life course aspect is currently being developed. The distribution of policies and procedures to ensuring ongoing preventative care, screening and developmental checks is shown on Map 3.1.

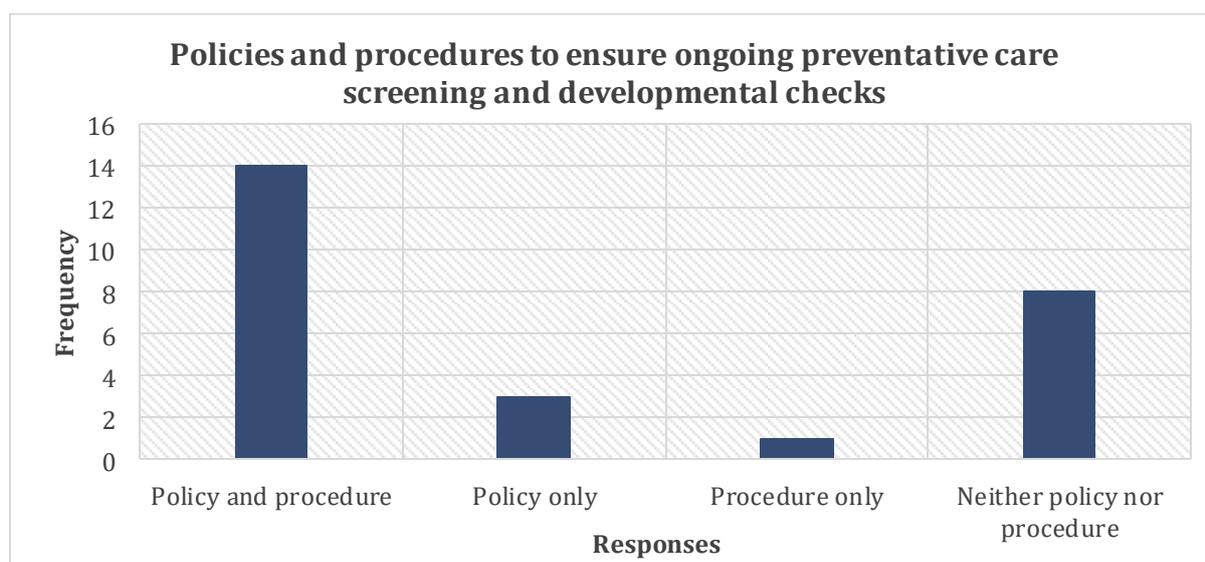
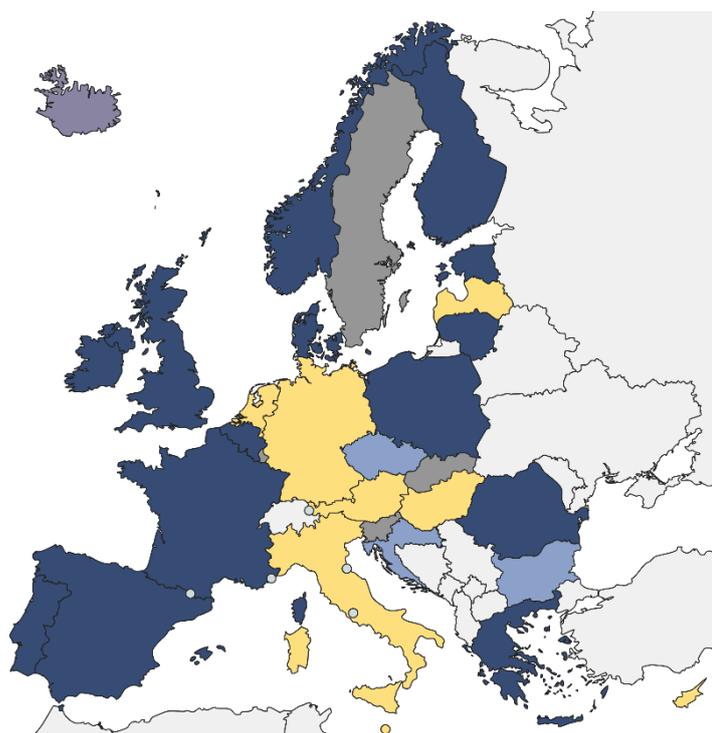


Figure 3.1: Policies and procedures to ensure ongoing preventative care, screening and developmental checks

### Policies and procedures to ensure ongoing preventative care, screening and developmental checks

-  Policies and procedures
-  Policy only
-  Procedure only
-  Neither policy nor procedure
-  No response
-  Non-Mocha country



Map 3.1: Policies and procedures to ensure ongoing preventative care, screening and developmental checks

#### 3.1.1.2. Policies and procedures to document and communicate screening results

The questionnaire included items on policies and procedures to document and communicate screening results to a) all care services involved in the care of the child and b) to the child's parents or guardians. One country did not respond to this item.

Eleven countries had both policies and procedures in place to document and communicate the results of such screening to all care services involved in the care of the child, for example, general practitioners or primary care paediatricians, community nurses, school health services and secondary care. However, ten countries had neither policies nor procedures for this purpose. A minority had either policies (n=1) or procedures (n=3). The specific policies were not identified for three countries and procedures for five countries. One country did not respond to both items.

More countries had policies and procedures to document and communicate screening results to parents than to communicate results to care services. Thirteen countries had both policies and procedures and eight had neither policies nor procedures. Two had policies only and three had procedures only. References for specific policies or procedures were not provided for five countries.

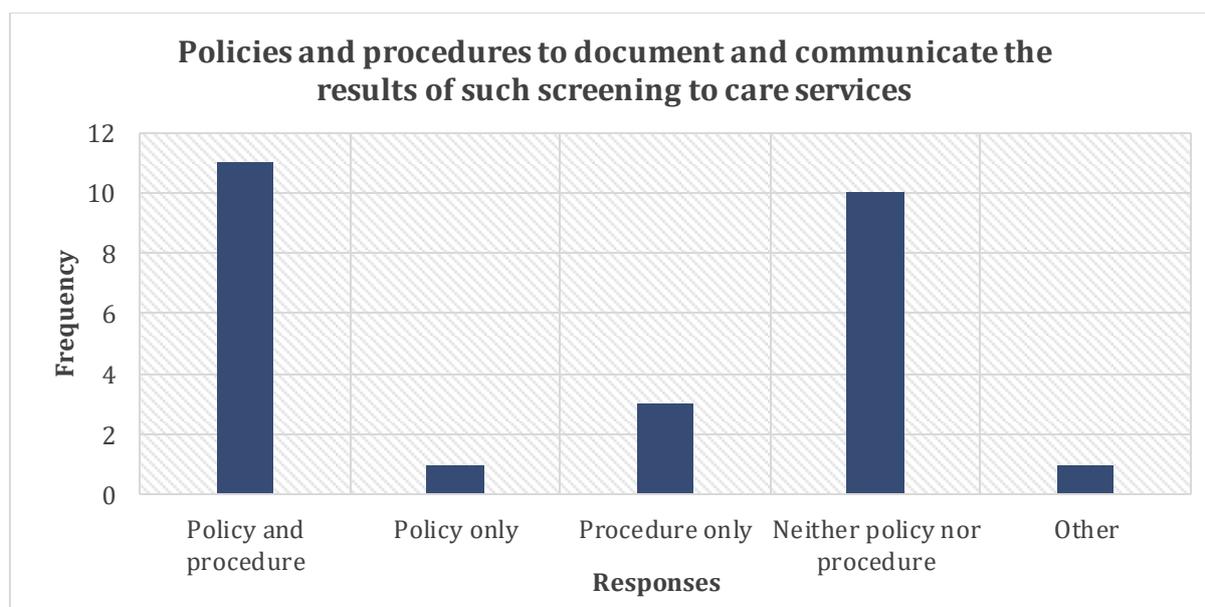


Figure 3.2: Policies and procedures to document and communicate the results of such screening to all care

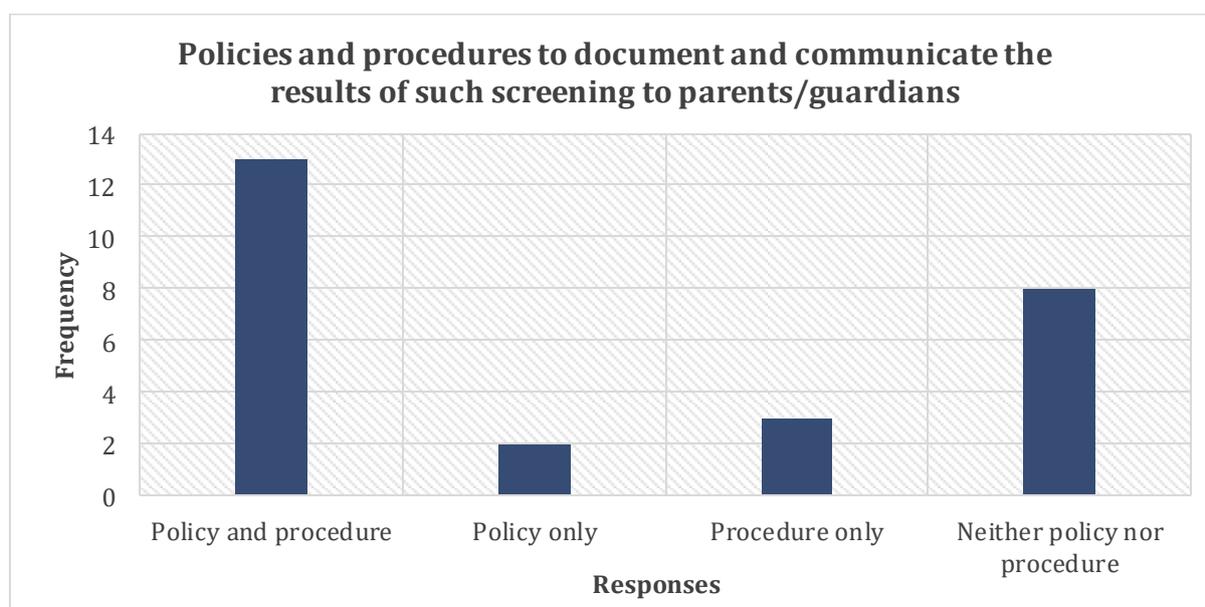


Figure 3.3: Policies and procedures to document and communicate the results of such screening to parents/guardians

### 3.1.1.3. Policies and procedures to assess family competencies that may influence providing care

The majority of countries (n=17) reported a lack of policies and procedures that assess family competencies, for example knowledge and ability, that may influence their capacity to provide care for a child with ASD. Nine countries reported that such policies or procedures were in place. The countries with policies and procedures to assess family competencies are displayed on Map 3.2.

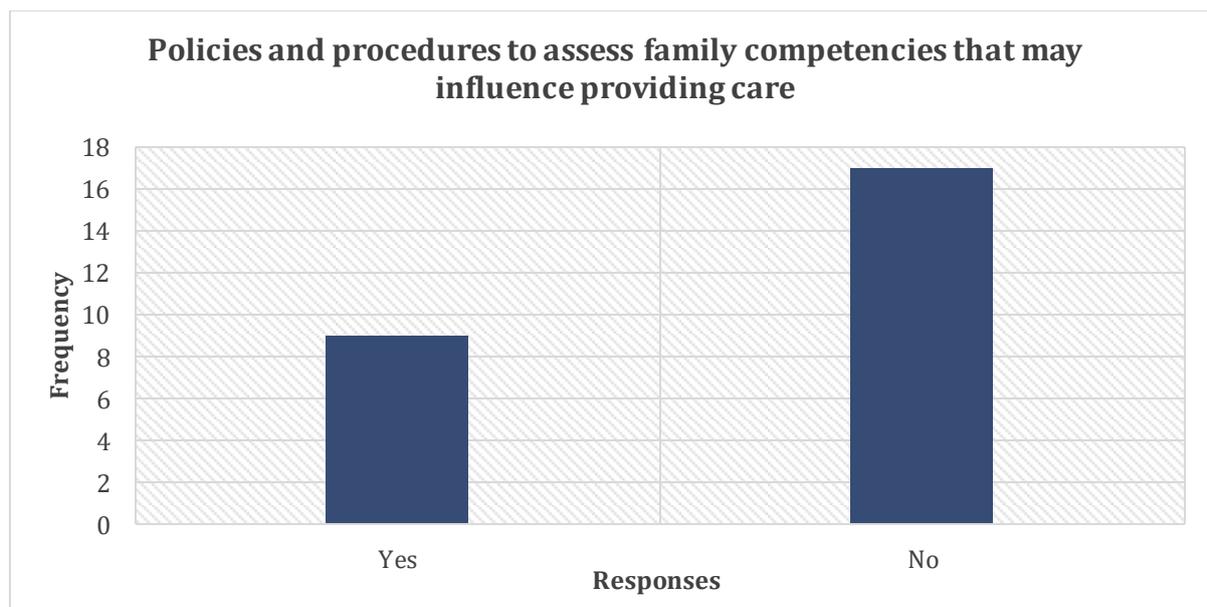
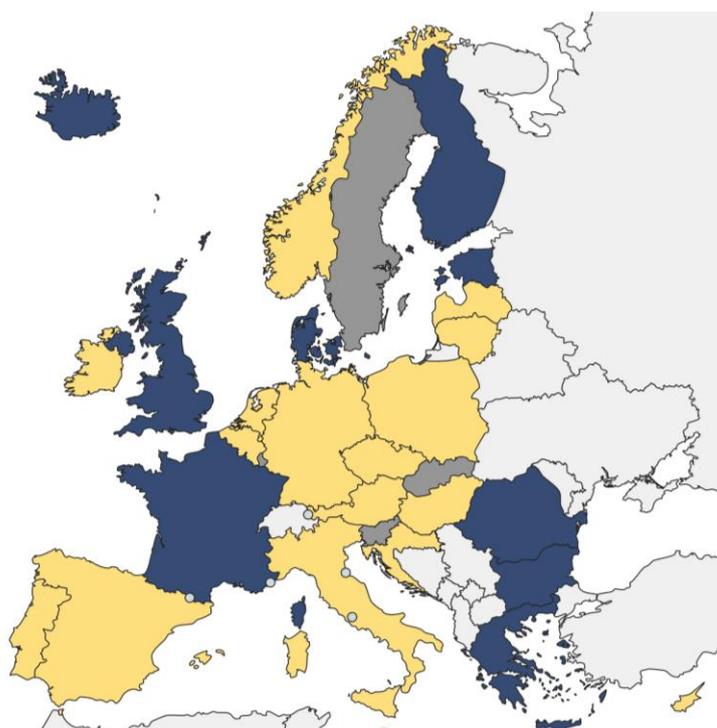


Figure 3.4: Policies or procedures to assess family competencies that may influence providing care

**Policies or procedures to assess family competencies that may influence providing care**

- Policies and procedures in place
- No policies or procedures
- No response
- Non-Mocha country



Map 3.2: Policies or procedures to assess family competencies that may influence providing care

**3.1.2. Access to Care**

**3.1.2.1. Systems to identify all healthcare and social care providers who care for children with ASD**

Less than half of the included countries (11 of 26) have systems in place to identify all healthcare providers caring for children with ASD, and even fewer countries (n=7) reported that

there was a system to identify all social care providers caring for children with ASD. Ireland reported a partial system for identifying healthcare providers and social care providers, in that only providers of residential or respite services are listed.

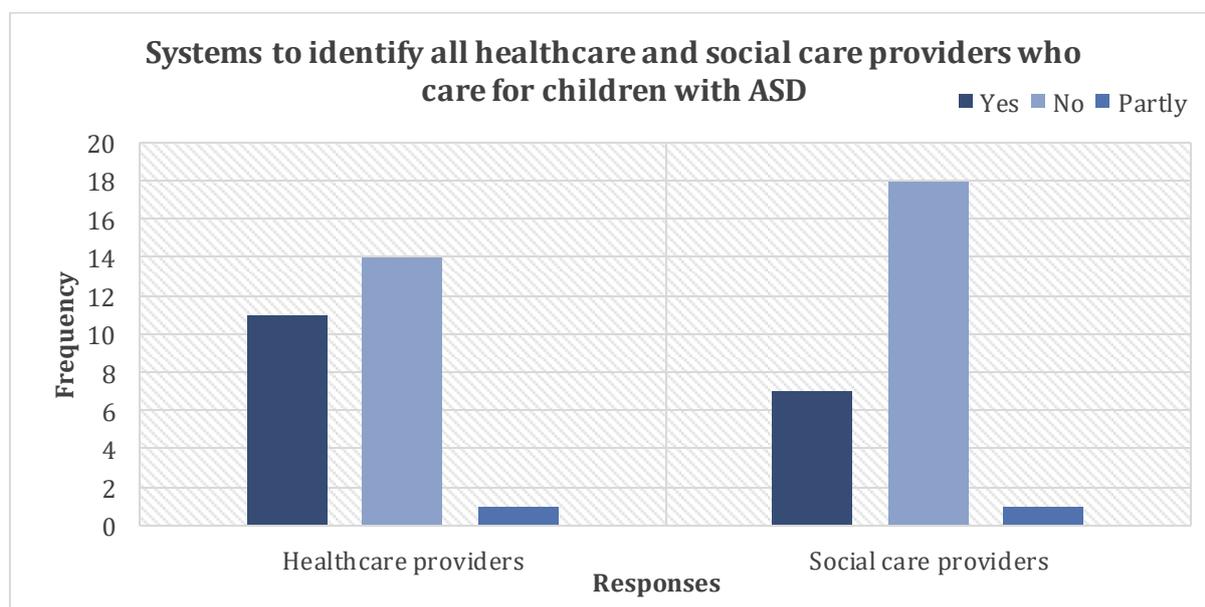


Figure 3.5: Systems to identify all healthcare and social care providers who care for children with ASD

### 3.1.2.2. Multi-disciplinary guideline of care for children with ASD

Half of the countries that responded reported having a multi-disciplinary guideline of care for children with ASD (n=13), while the other half reported that no such guideline was in place. The locations of countries with multidisciplinary guidelines are shown on Map 3.3.

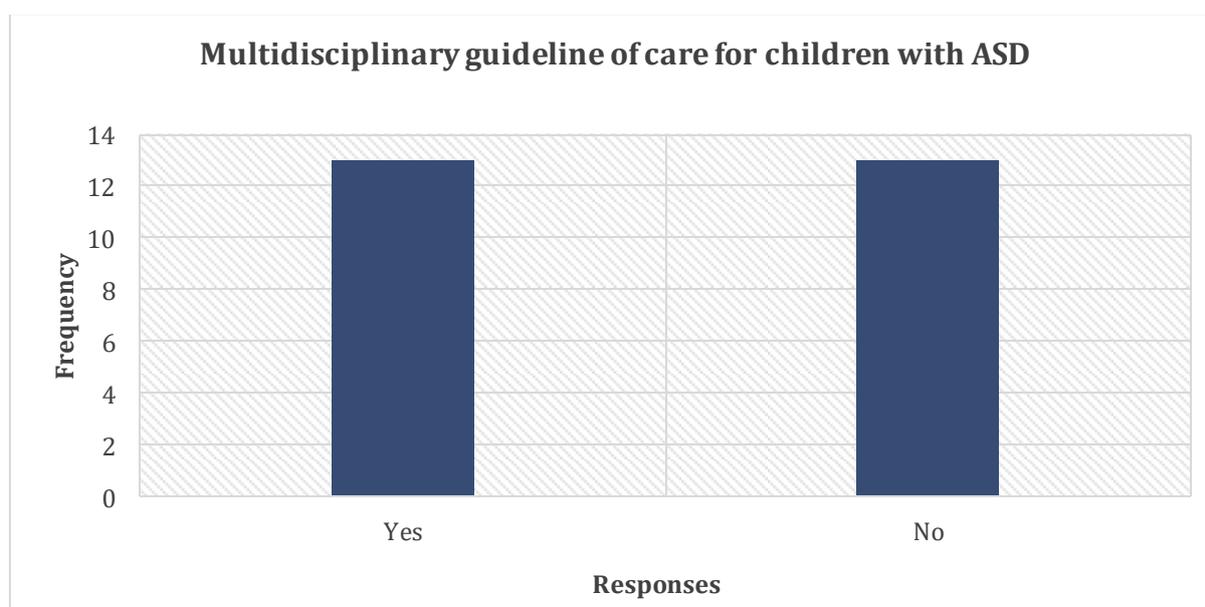
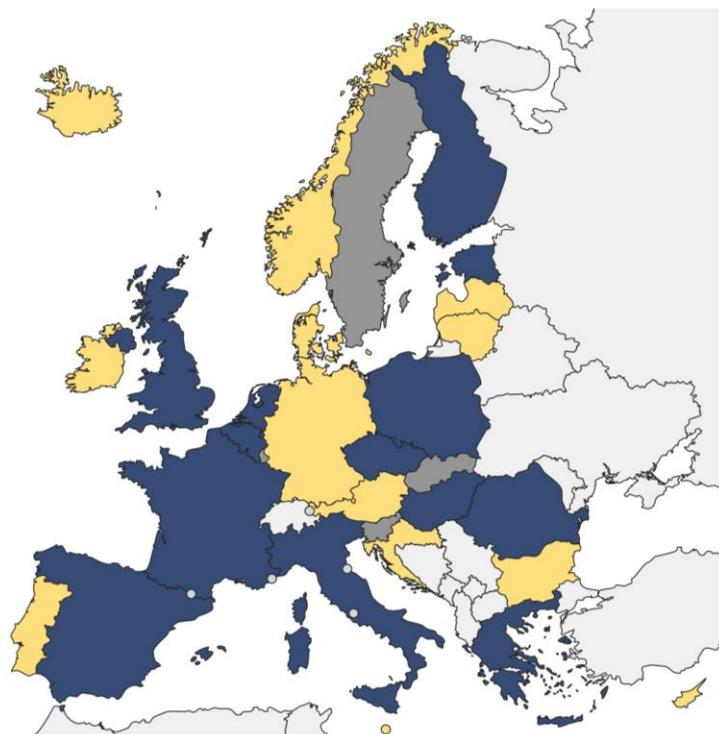


Figure 3.6: Multi-disciplinary guideline of care for children with ASD

### Multi-disciplinary guideline of care for children with ASD

- Multi-disciplinary guideline
- No multi-disciplinary guideline
- No response
- Non-Mocha country



Map 3.3: Multi-disciplinary guideline of care for children with ASD

#### 3.1.2.3. Policies or procedures to provide an overview of the interface between the primary, secondary and social care system

The majority of countries (n=18) did not have a policy or procedure to provide an overview of the interface between the health care and social care system responsible for primary and secondary care for a child with ASD. Eight countries reported that they did have such policies.

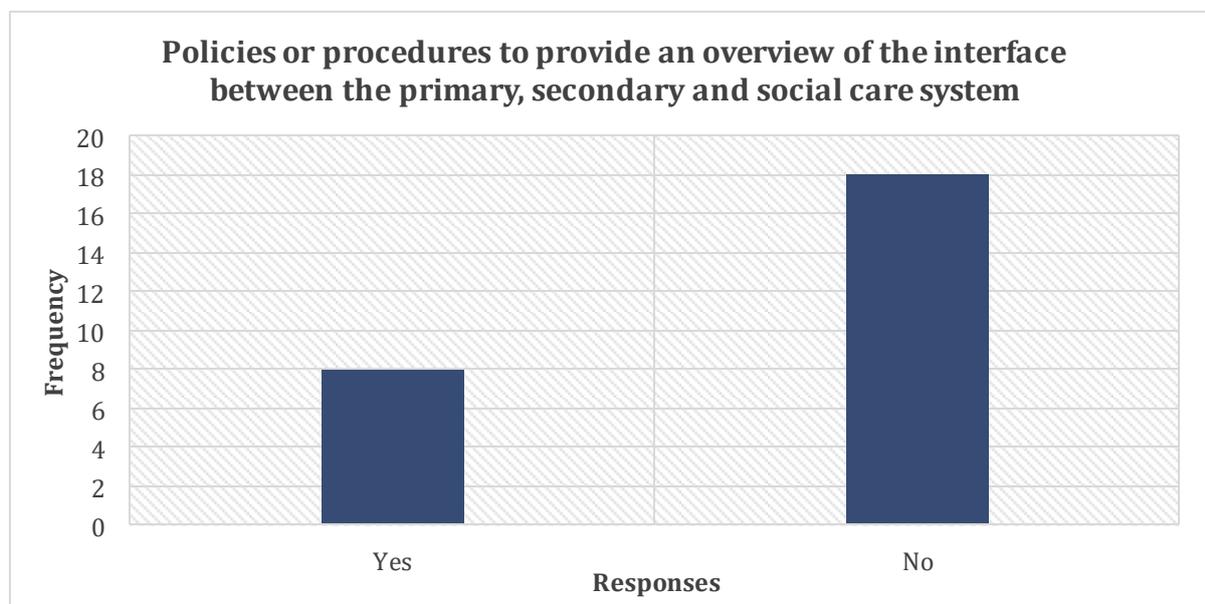


Figure 3.7: Policies or procedures to provide an overview of the interface between the primary, secondary and social care system

### 3.1.2.4. Policies or procedures to ensure children with ASD are cared for by the same healthcare and social care teams every time

Eleven responding countries have policies or procedures in place to ensure that children with ASD are cared for by the same team of healthcare providers every time, but a majority countries did not have such policies or procedures (n=15). With regards to social care teams, fewer countries had policies or procedures in place to ensure children with ASD are cared for by the same team each time (n=9).

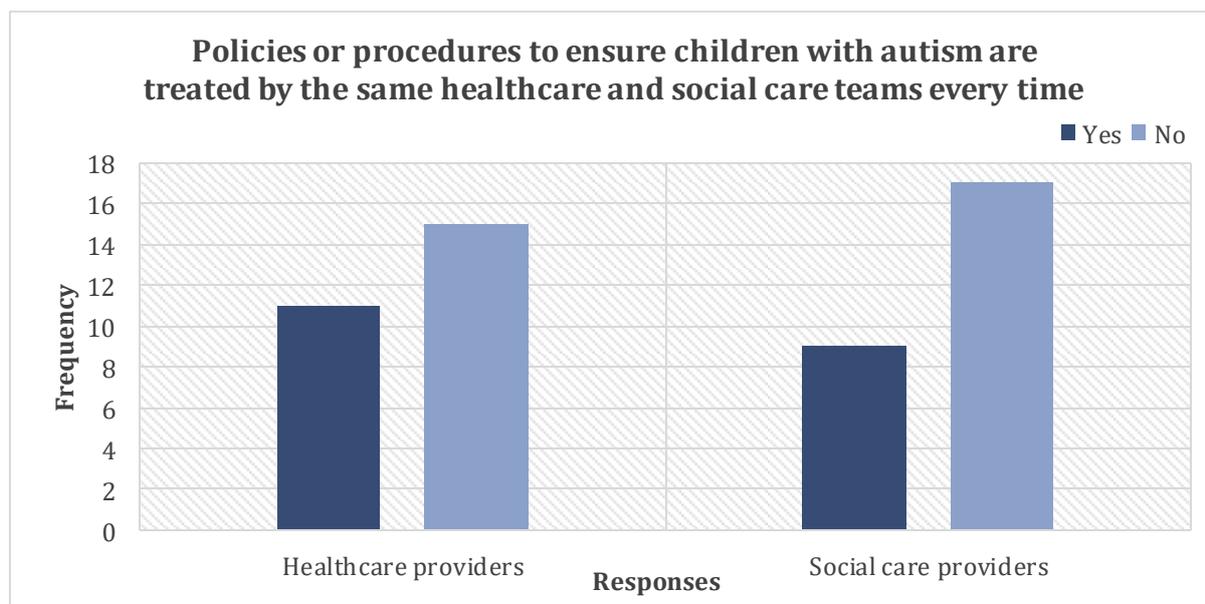


Figure 3.8: Policies or procedures to ensure children with ASD are treated by the same healthcare and social care teams every time

### 3.1.2.5. A child with ASD can access primary care regardless of care provided in secondary care and vice versa.

A large majority of countries (n=24) reported that a child with ASD can access primary care regardless of care provided in secondary care and vice versa, with two countries (Cyprus and Norway) reporting that this was not possible in their countries.

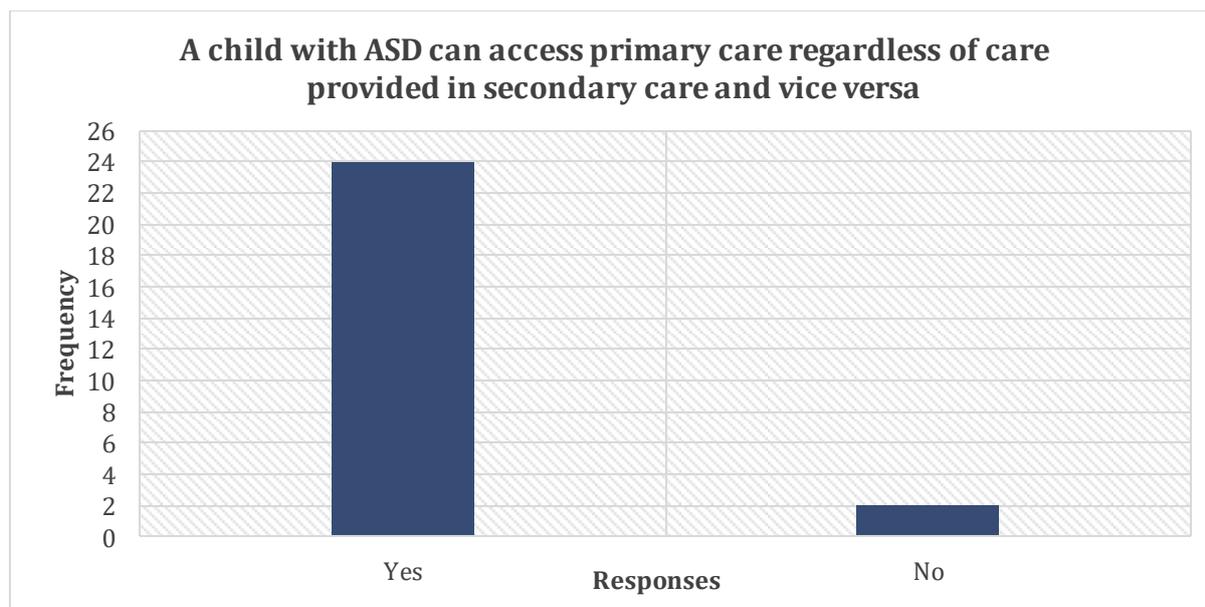


Figure 3.9: A child with ASD can access primary care regardless of care provided in secondary care and vice versa

### 3.1.2.6. Provision of transportation to care services for children with ASD

The majority of countries reported that transportation to care services for children with ASD was provided by parents with support from the state (n=16). Only five countries reported that healthcare providers offered transportation to care services for children with ASD and ten reported that social care providers did so. Four countries reported that transport was partially available via the social care provider, with two of these also stating transport is partially available via the healthcare provider. Reasons for this partial availability include funding allocation and regional variation, or it may be available only for necessary procedures. One country did not respond to this item.

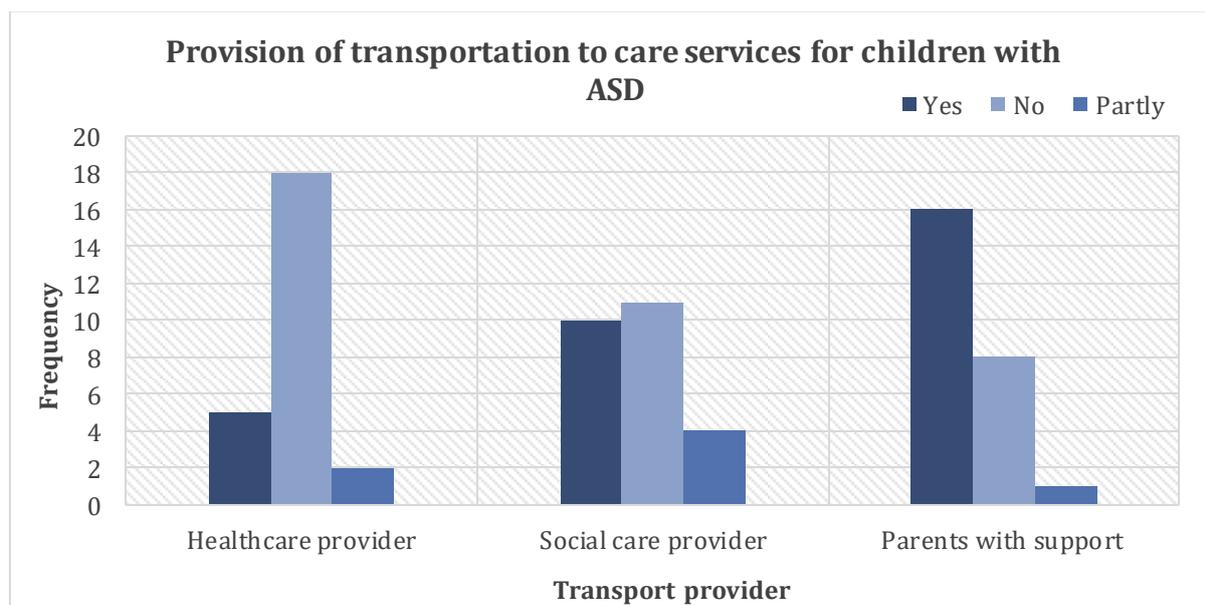


Figure 3.10: Provision of transportation to care services for children with ASD

### 3.1.2.7. Policies or procedures to ensure that all information provided to families of children with ASD is linguistically appropriate

The majority of countries lacked policies or procedures to ensure that all information provided to families of children with ASD is linguistically (n=16) or culturally (n=18) appropriate. Four countries had both policies and procedures to ensure information given to families is linguistically appropriate and two had policies and procedures to ensure information is culturally appropriate. A few countries had either policies or procedures regarding these matters and one country did not respond to this item (Iceland).

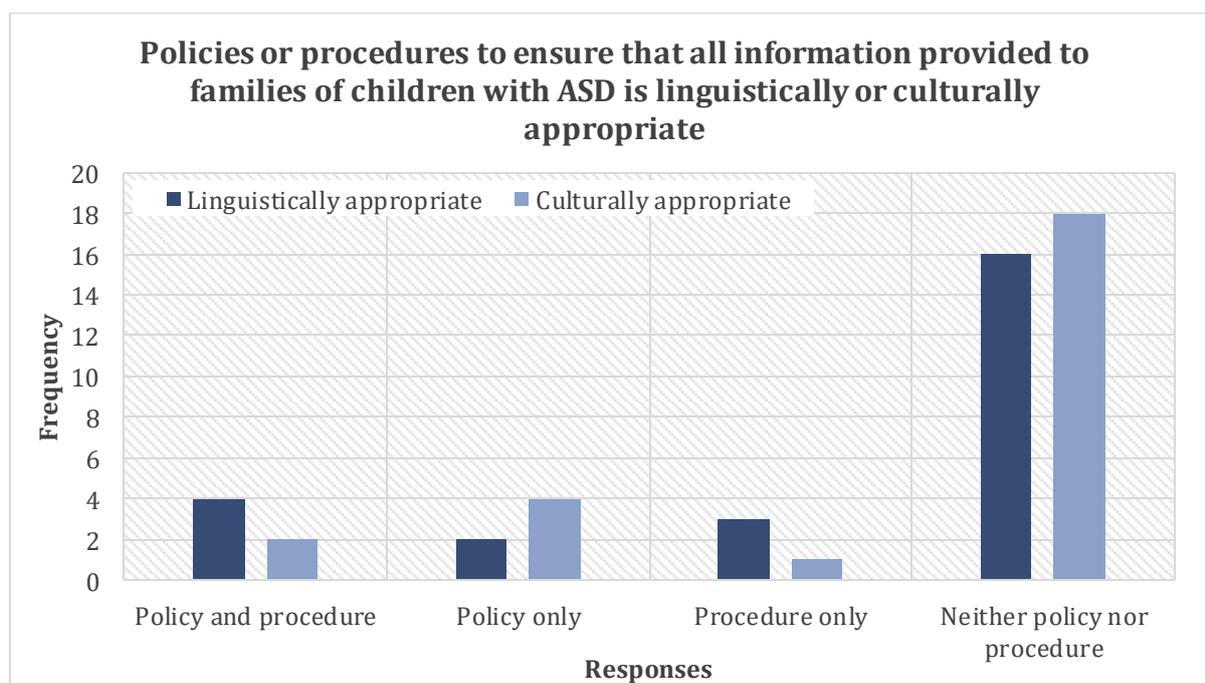


Figure 3.11: Policies or procedures to ensure that all information provided to families of children with ASD is linguistically appropriate

### 3.1.3. Care Coordination

#### 3.1.3.1. Policies and procedures promoting access to care coordination for children diagnosed with ASD

Twelve countries reported having both policies and procedures promoting access to care coordination for children with ASD, and eight reported having no such policies or procedures. Six countries reported having policies only, but none had procedures only; it may be that care coordination is policy-led rather than procedure-led. Specific policies or procedures were not identified for five countries.

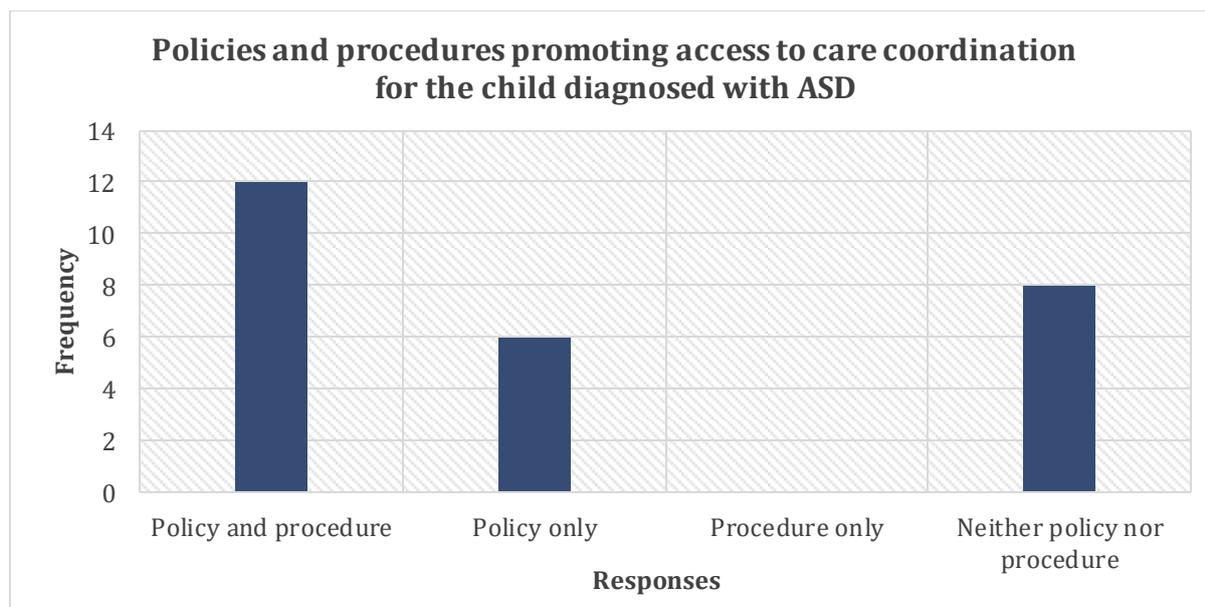


Figure 3.12: Policies and procedures promoting access to care coordination for children diagnosed with ASD

### 3.1.3.2. There is a specific care pathway for children with ASD

Eight countries reported that there is no specific care pathway for children with ASD. Only three countries reported that there is a specific care pathway for children with ASD, although fifteen answered that there is a partial care pathway. Respondents reported partial care pathways due to regional variation or due to the pathway covering only the diagnosis stage of their care, for example. Responses are presented on Map 3.4.

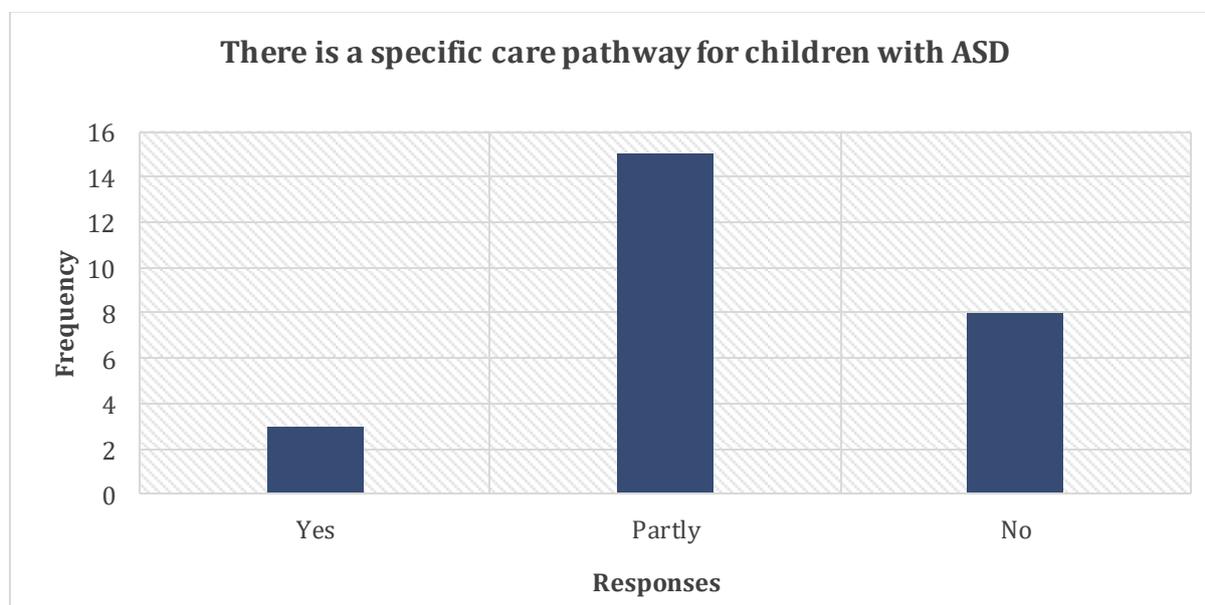
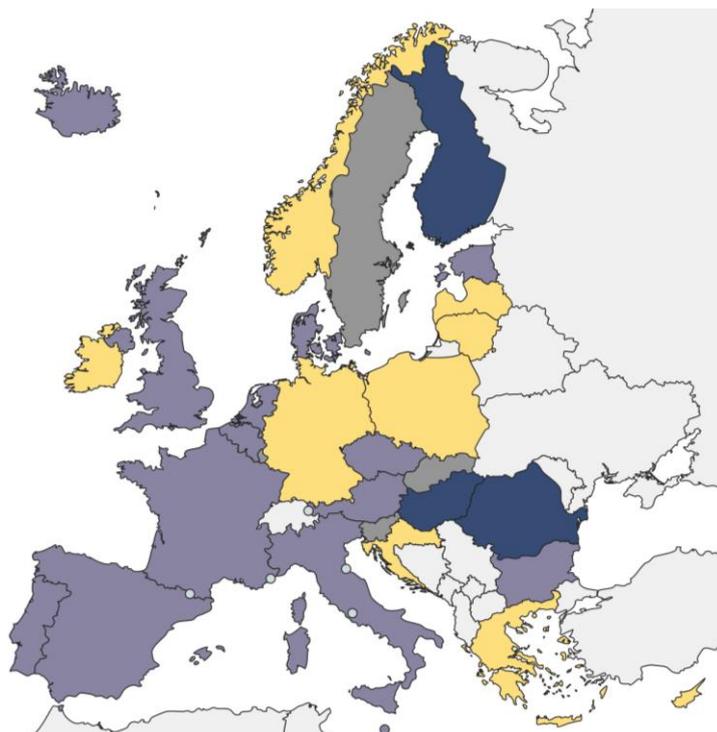


Figure 3.13: There is a specific care pathway for children with ASD

**There is a specific care pathway for children with ASD**

- Specific care pathway in place
- Partial care pathway
- No care pathway
- No response
- Non-Mocha country



Map 3.4: There is a specific care pathway for children with ASD

**3.1.3.3. Policies or procedures that clearly describe the role of each provider in a care pathway for children with ASD**

Of the eighteen countries that reported having a full or partial pathway for children with ASD, eight countries reported having a clear description of the role of each care provider in the pathway. A further two countries (Estonia and the Netherlands) have a partial description of roles, in that only some care providers are included or only part of the pathway is specified. Eight of the eighteen countries with a care pathway do not have policies or procedures describing the roles of care providers.

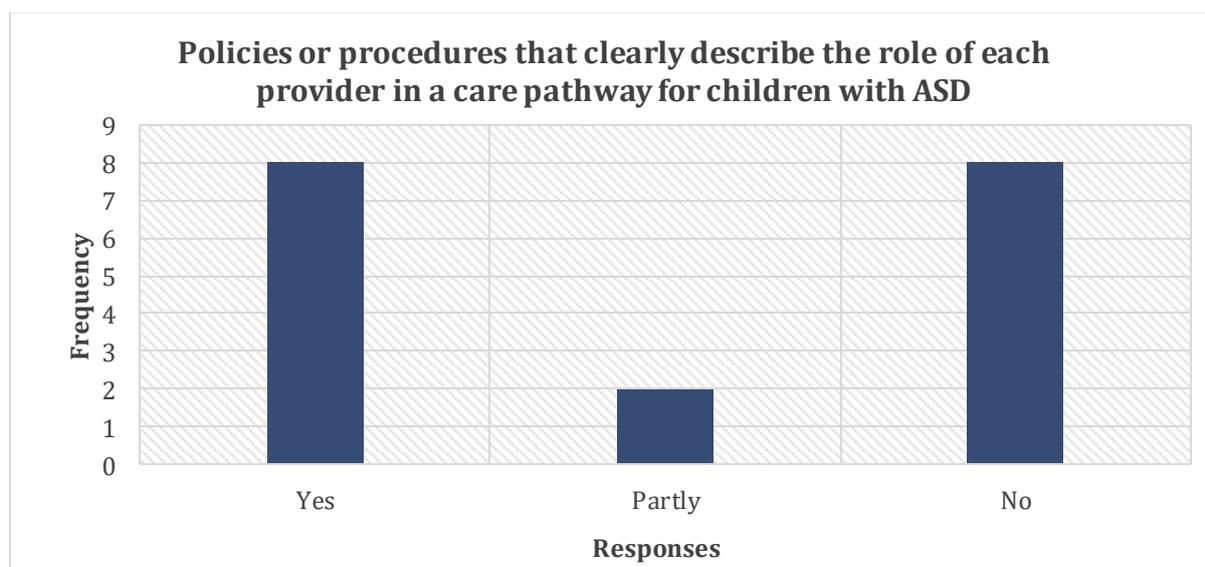


Figure 3.14: Policies or procedures that clearly describe the role of each provider in a care pathway for children with ASD

### 3.1.3.4. Procedures to ensure that all providers in a care pathway for children with ASD participate in care coordination

Of the eighteen countries that reported having a care pathway for children with ASD, nine responded that there were no procedures to ensure that all providers in a care pathway for children with ASD participate in care coordination. Eight countries reported that there are such procedures. The Netherlands indicated that there were partial procedures.

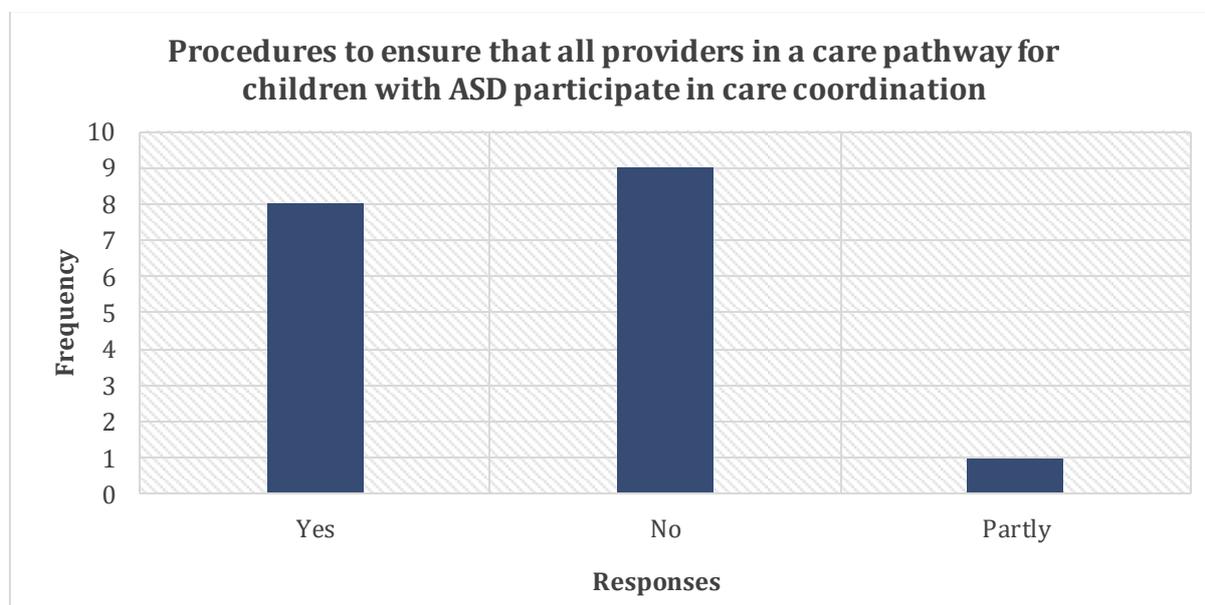


Figure 3.15: Procedures to ensure that all providers in a care pathway for children with ASD participate in care coordination

### 3.1.3.5. Policy or procedure to integrate primary and secondary care in the care pathway for children with ASD

Of the seventeen responses included for this item, nine indicated that there is an integration procedure or policy to integrate primary and secondary care and eight reported a lack of no such policies or procedures. However, two countries did not answer the question and the countries with no care pathway for children with ASD were excluded (n=8), except for Lithuania, where a specific procedure integrating primary and secondary care for children with ASD was reported. Eight of the nine countries reported that these policies or procedures facilitate continuity between primary and secondary care.

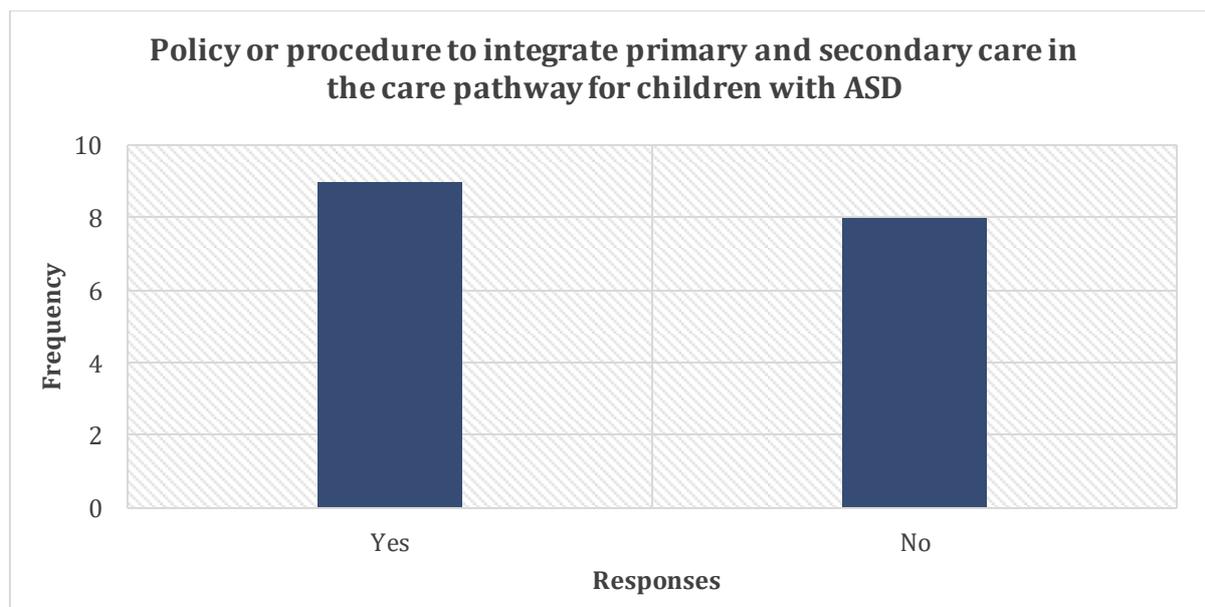


Figure 3.16: Policy or procedure to integrate primary and secondary care in the care pathway for children with ASD

### 3.1.3.6. Procedures ensuring a personalised written care plan for children diagnosed with ASD

Fifteen countries reported having procedures ensuring a personalised written care plan for children with ASD and the Netherlands reported having partial procedures guaranteeing a personalised written care plan. Nine indicated that there were no such procedures and one country did not respond to this question. Responses are presented on Map 3.5.

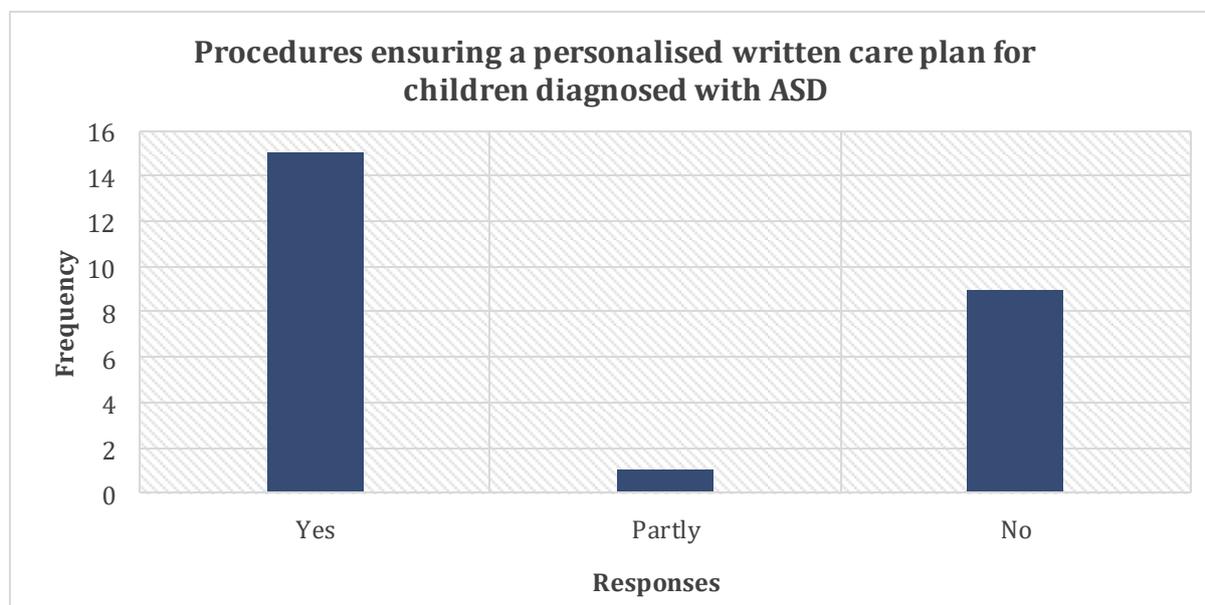
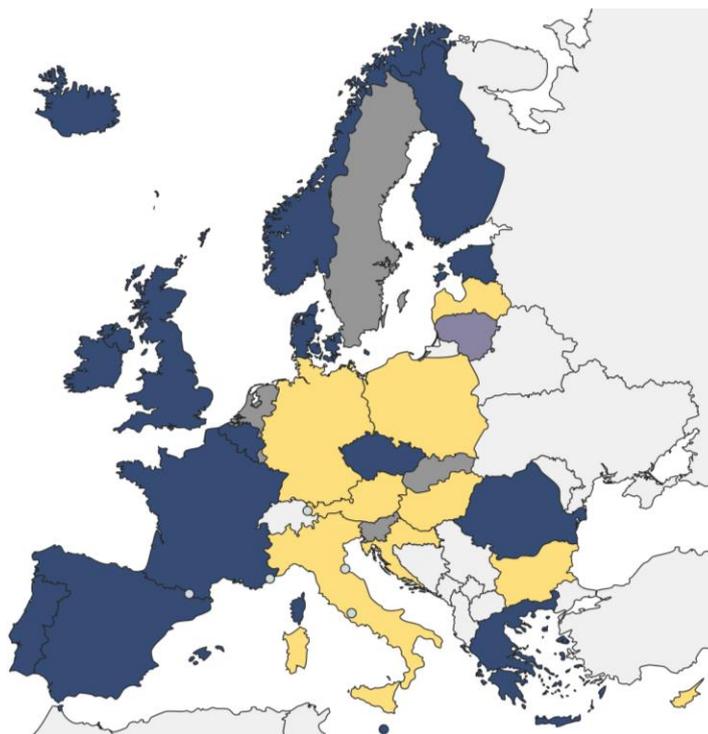


Figure 3.17: Procedures ensuring a personalised written care plan for children diagnosed with ASD

### Procedures ensuring a personalised written care plan for children diagnosed with ASD

-  Personalised written care plan
-  Partial care plan
-  No personalised written plan
-  No response
-  Non-Mocha country



Map 3.5: Procedures ensuring a personalised written care plan for children diagnosed with ASD

#### 3.1.3.7. Persons consulted with in the development of the personalised written plan of care for a child with ASD

While sixteen countries that reported having full or partial procedures ensuring a personalised written plan of care, more countries responded to questions regarding the persons consulted during the making of the plan and the elements integrated into the plan (see 3.1.3.8 below). Understood together with the qualitative comments, it does not seem unusual that written personalised care plans are commonly made despite the absence of policies and procedures.

Therefore, of the 21 countries in which personalised written care plans are reported, nineteen indicated that the parents or guardians are consulted and eighteen indicated that healthcare providers are consulted in the development of this plan. Fourteen reported that social care providers are consulted.

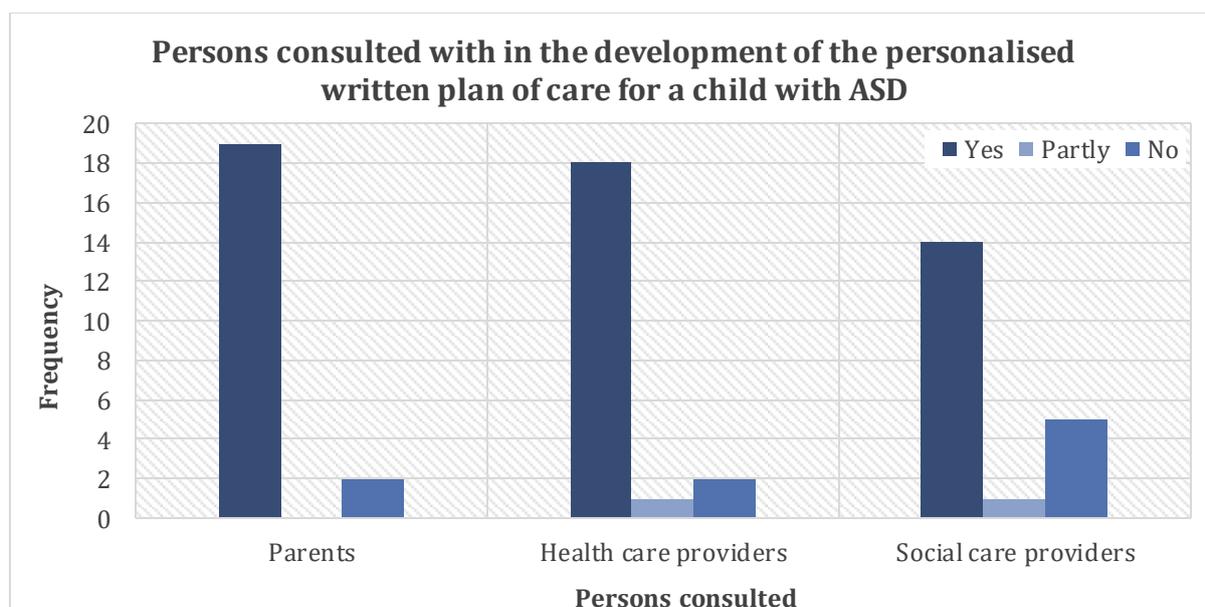


Figure 3.18: Persons consulted with in the development of the personalised written plan of care for a child with ASD

### 3.1.3.8. Elements of care integrated in the personalised written care plan for a child with ASD

All nineteen countries reported that developmental health is incorporated into the personalised written plan of care, eighteen included physical health and seventeen countries included mental health. The least common element of care included in the personalised written care plan was oral health (n=10).

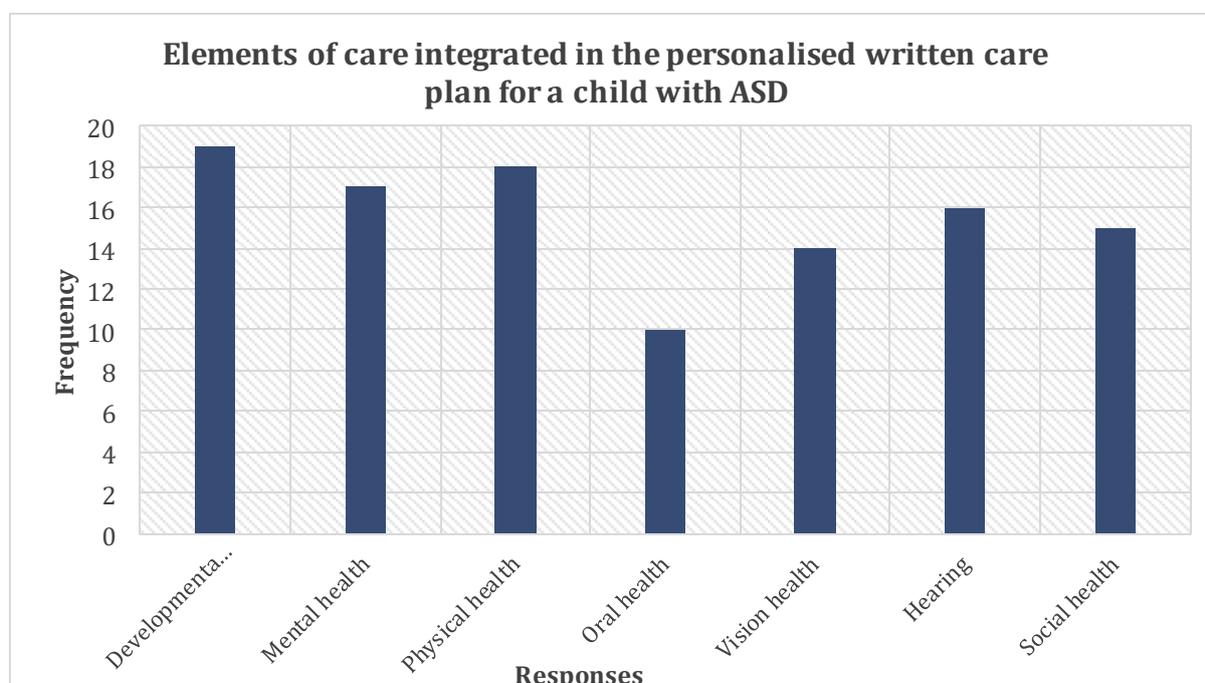


Figure 3.19: Elements of care that are integrated in the personalised written care plan for a child with ASD

### 3.1.3.9. Hospitals that provide mental health care for children with ASD have a discharge planning coordinator to organise transition to home

The majority of responding countries (n=13) reported that hospitals providing mental health care for children with ASD have a discharge planning coordinator to organise transition to home or other community-based settings. Nine countries reported that there were no such discharge coordinators caring for children with ASD, and three countries did not answer this item.

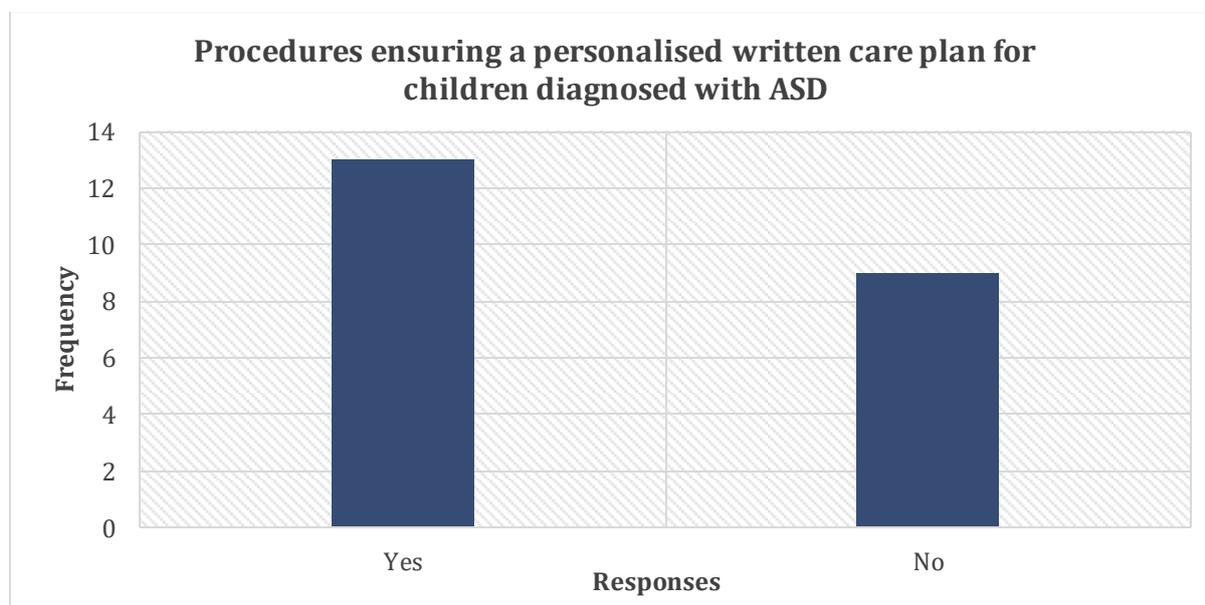


Figure 3.20: Hospitals that provide mental health care for children with ASD have a discharge planning coordinator to organise transition to home

### 3.1.4. Community-Based Services and Support

#### 3.1.4.1. Community-based services are a key component of the care approach for children with ASD

Most countries (n=16) agreed that community-based services, such as local initiatives or voluntary organisations, are key components of the care approach for children with ASD. Ten said they are not key in their countries.

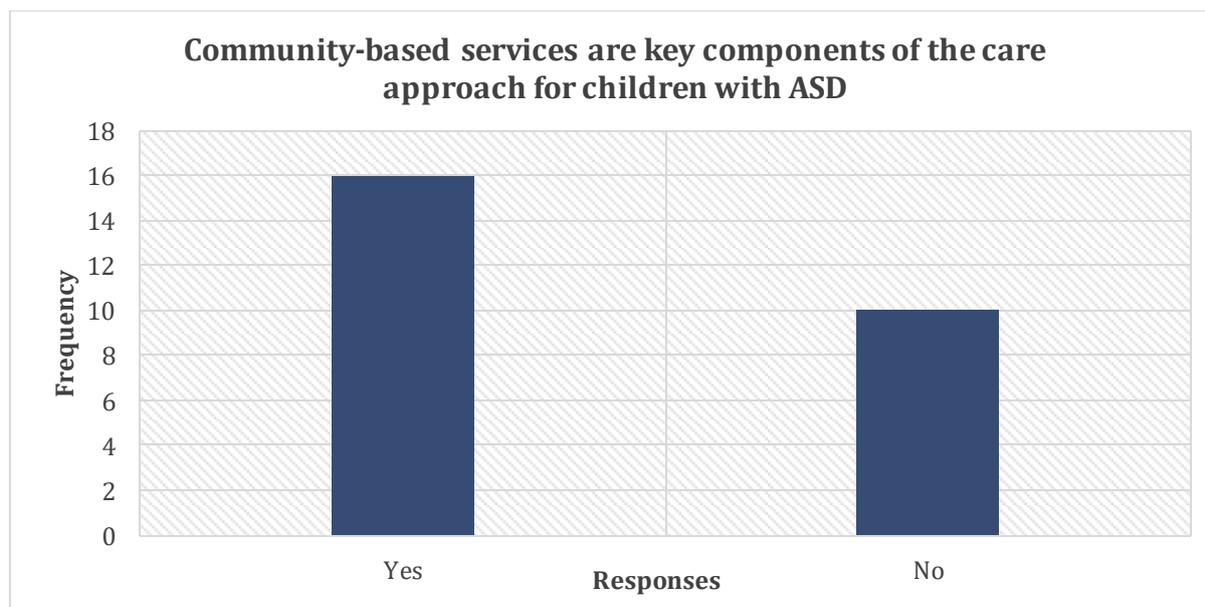


Figure 3.21: Community-based services are key components of the care approach for children with ASD

### 3.1.4.2. Family advocacy groups are involved in making recommendations to home and community-based services

The majority of countries (n=19) reported that family advocacy groups are involved in making recommendations to home and community-based services caring for children with ASD. Seven countries reported that family advocacy groups do not have this role.

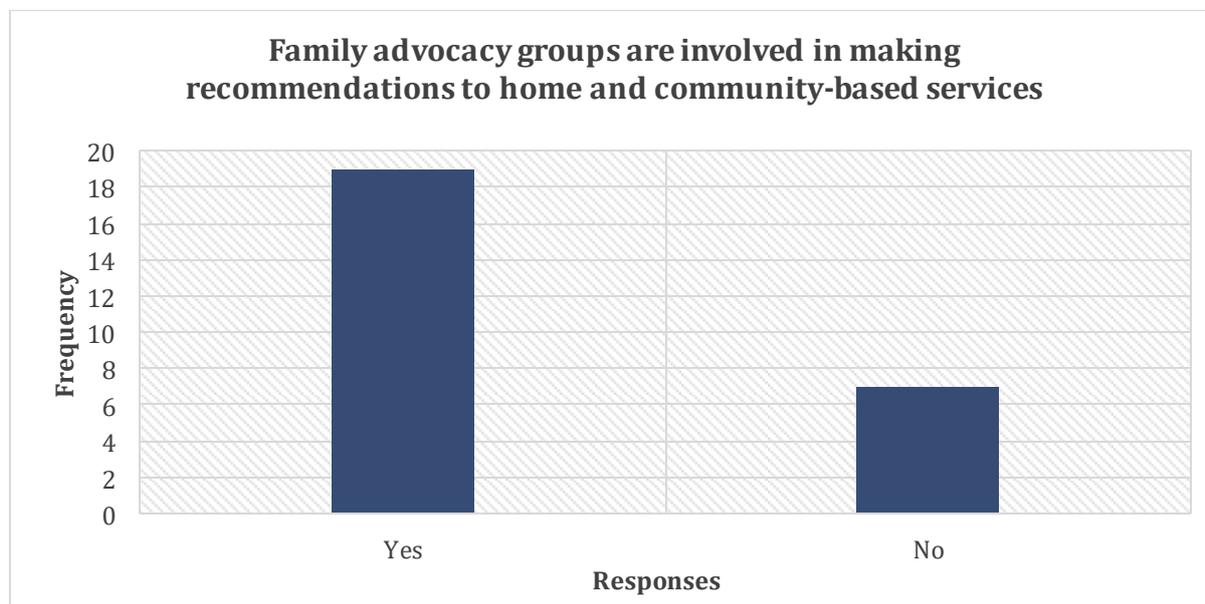
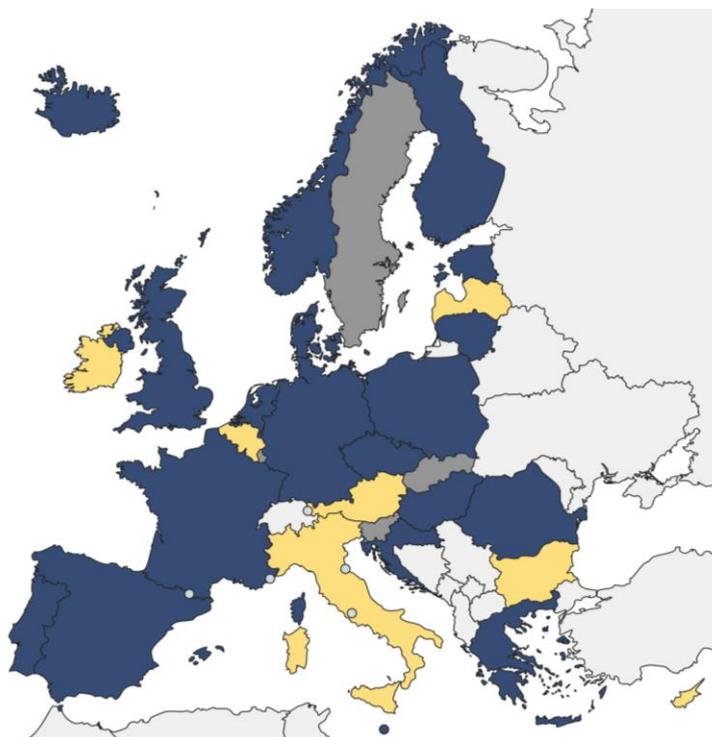


Figure 3.22: Family advocacy groups are involved in making recommendations to home and community-based services

**Family advocacy groups are involved in making recommendations to home and community-based services**

- Yes
- No
- No response
- Non-Mocha country



Map 3.6: Family advocacy groups are involved in making recommendations to home and community-based services

**3.1.4.3. The parents, guardians and siblings of children with ASD have access to professional psychosocial support**

The majority of countries (n=22) reported that the parents, guardians and siblings of children with ASD have access to professional psychosocial support. The four countries in which support was not available were Bulgaria, Hungary, Latvia and Malta.

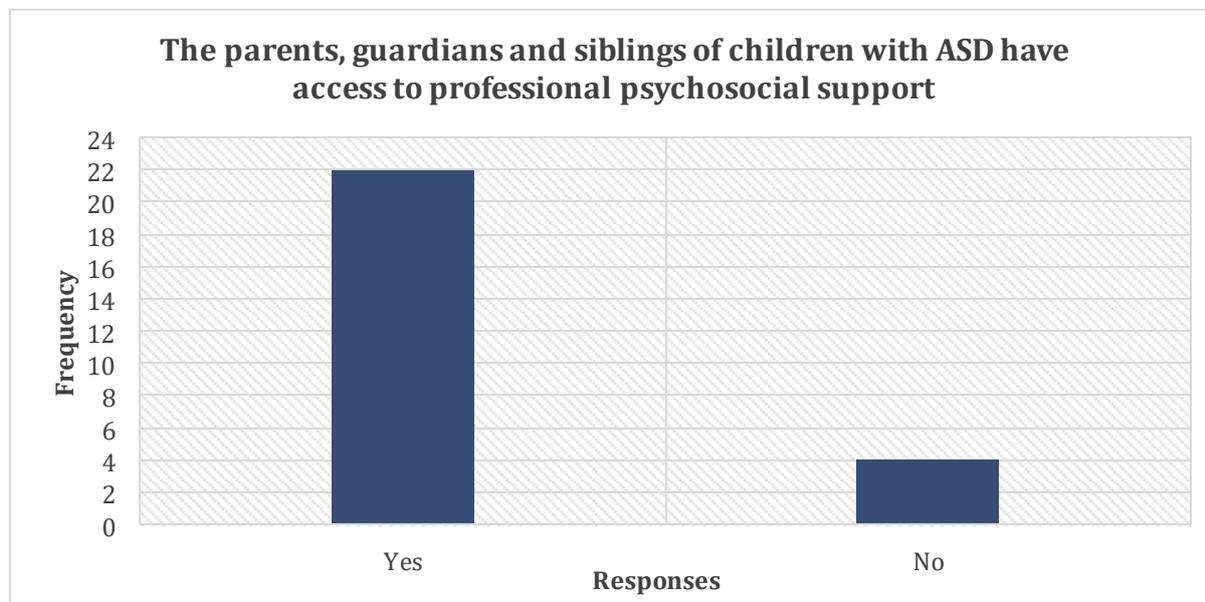


Figure 3.23: The parents, guardians and siblings of children with ASD have access to professional psychosocial support

### 3.1.4.4. Respite care is available for children with ASD

The majority of countries (n=23) replied that there is respite care available in their country for children with ASD and their families, but three answered that there is no respite care available in relation to ASD (Bulgaria, Lithuania and Malta).

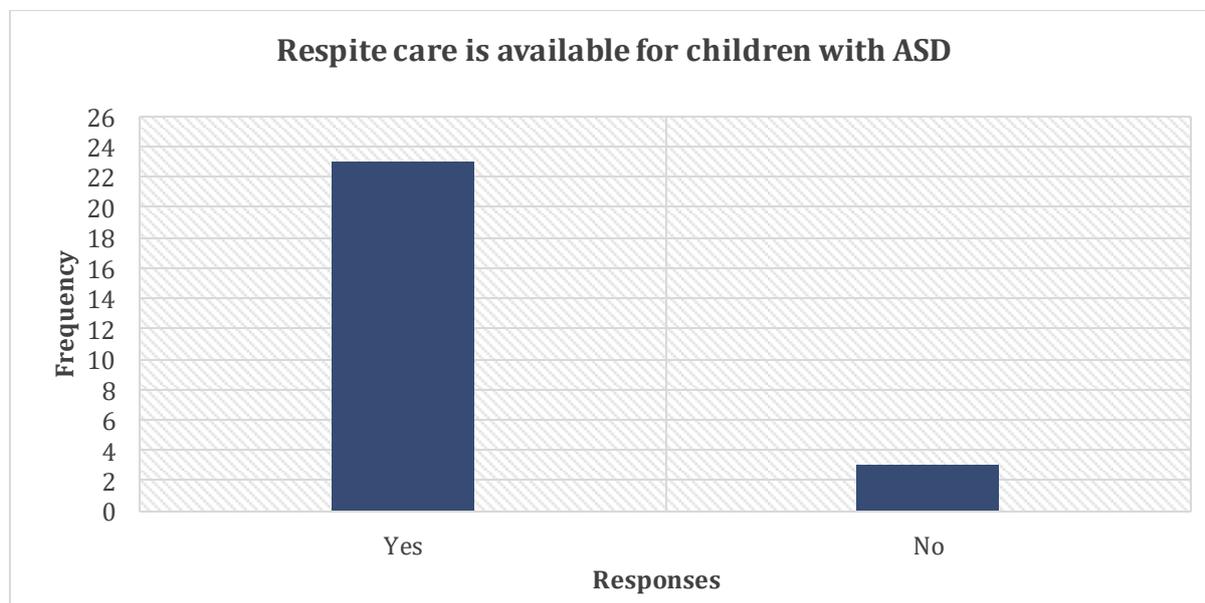


Figure 3.24: Respite care is available for children with ASD

### 3.1.4.5. Providers of respite care available for children with ASD

Of the countries where respite care was reported (n=23), most reported that respite care for children with ASD is provided in the voluntary sector (n=16), although it is not available in the voluntary sector in seven countries. Respite care for children with ASD is provided by the state in fifteen countries and in the private sector in twelve countries. Romania reported that respite care services are narrowly restricted to certain regions.

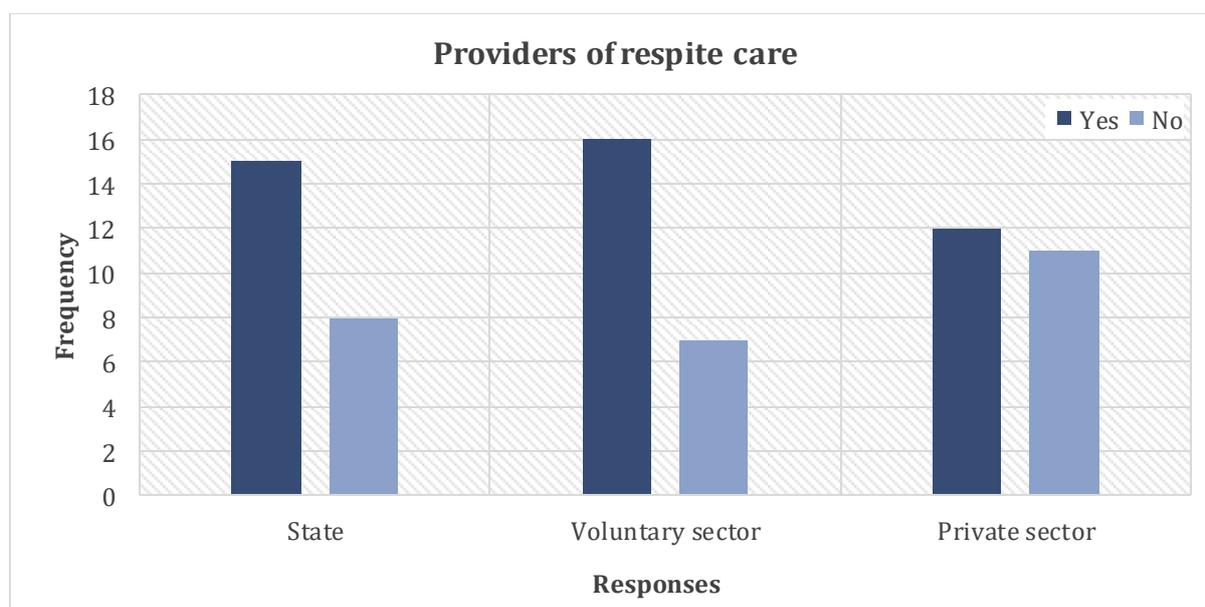


Figure 3.25: Providers of respite care available for children with ASD

### 3.1.4.6. Children with ASD are offered the opportunity to acquire skills or education according to their individual needs

The majority of countries (n=23) reported that opportunities to participate in education and training tailored to the individual are offered to children with ASD, while Iceland indicated that this was partly available and Latvia or Bulgaria reported no tailored education opportunities.

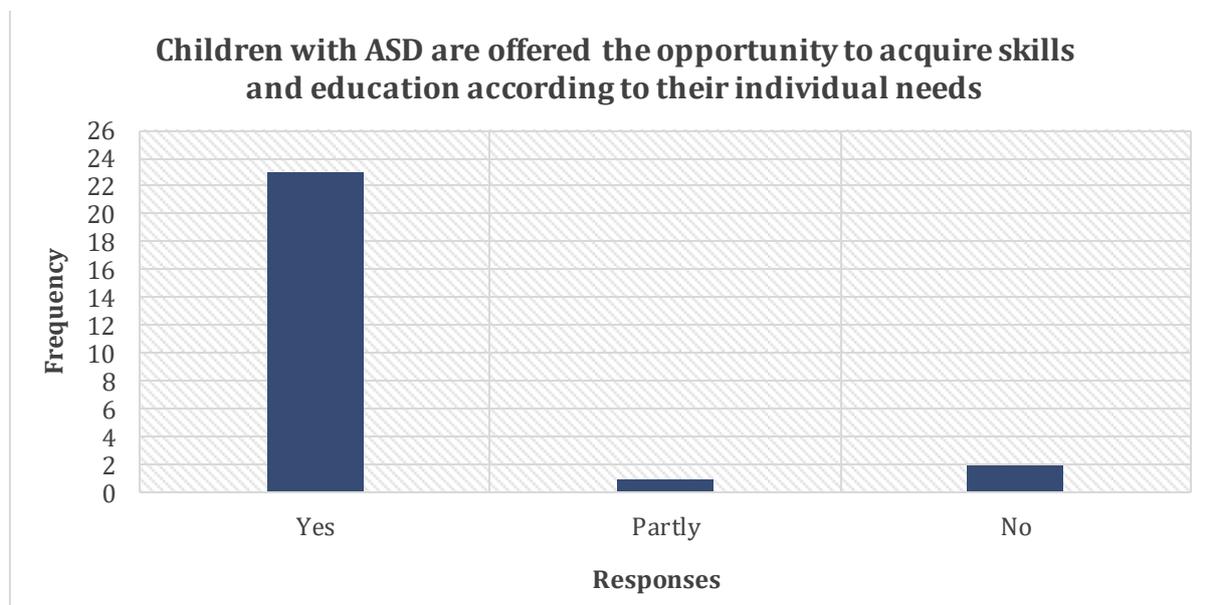


Figure 3.26: Children with ASD are offered the opportunity to acquire skills and education according to their individual needs

### 3.1.5. Family Professional Partnership

#### 3.1.5.1. Parents and guardians of children with ASD are invited to participate in the development of policies and procedures affecting their children

Sixteen countries reported that parents and guardians of children with ASD are invited to participate in the development of policies and procedures affecting their children, while ten said that parents were not involved in this way.

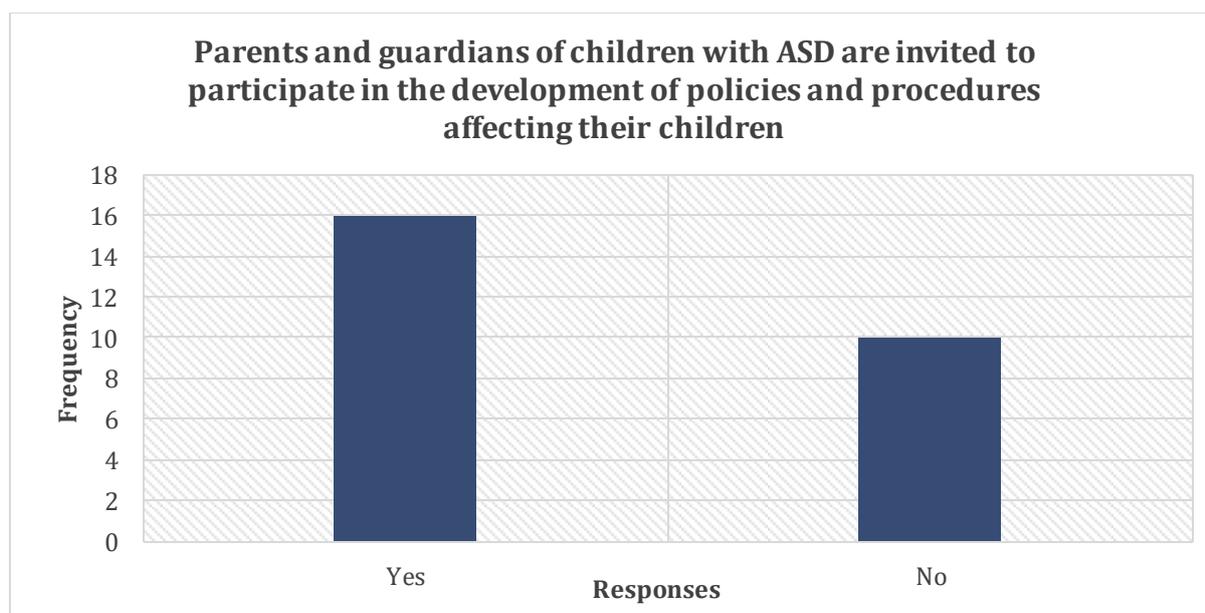


Figure 3.27: Parents and guardians of children with ASD are invited to participate in the development of policies and procedures affecting their children

### 3.1.5.2. Parents and guardians of children with ASD are included in national quality improvement initiatives for ASD

Fifteen countries reported that parents and guardians of children with ASD are included in national quality improvement initiatives for ASD, but in eleven countries they are not included in this way.

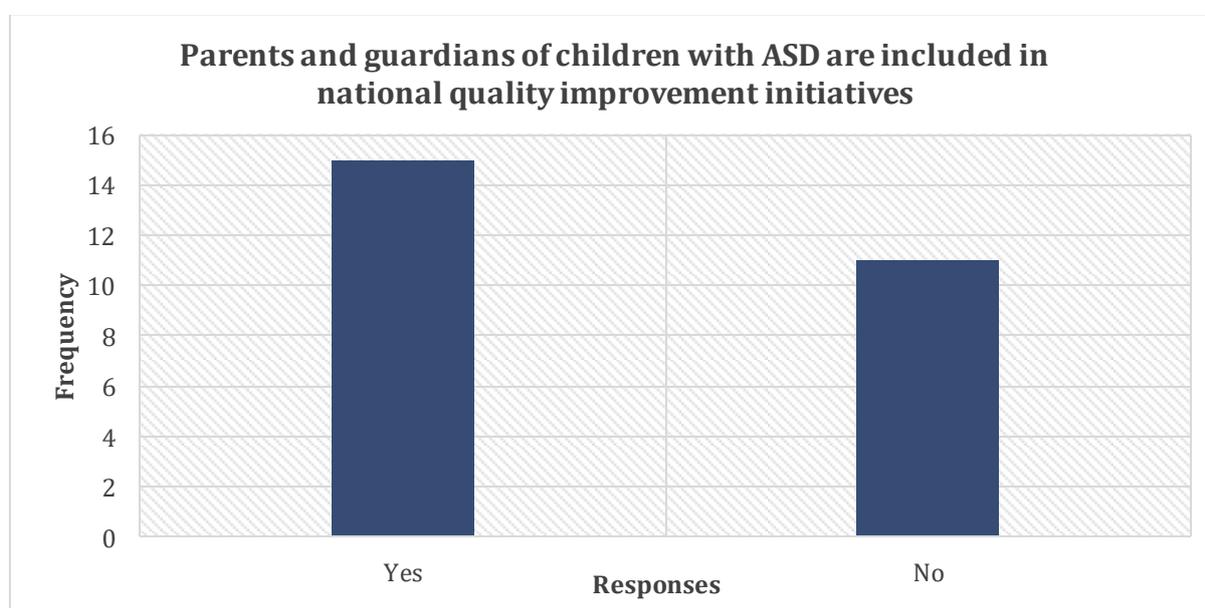


Figure 3.28: Parents and guardians of children with ASD are included in national quality improvement initiatives for ASD

### 3.1.5.3. Parents and guardians of children with ASD review materials for the public regarding ASD to ensure they are culturally or linguistically appropriate

Eight countries reported that parents and guardians of children with ASD review materials for the public regarding ASD to ensure they are culturally or linguistically appropriate, but in seventeen countries parents and guardians are not involved in reviewing these materials. In the UK, this is unclear, but likely happens as part of best practice.

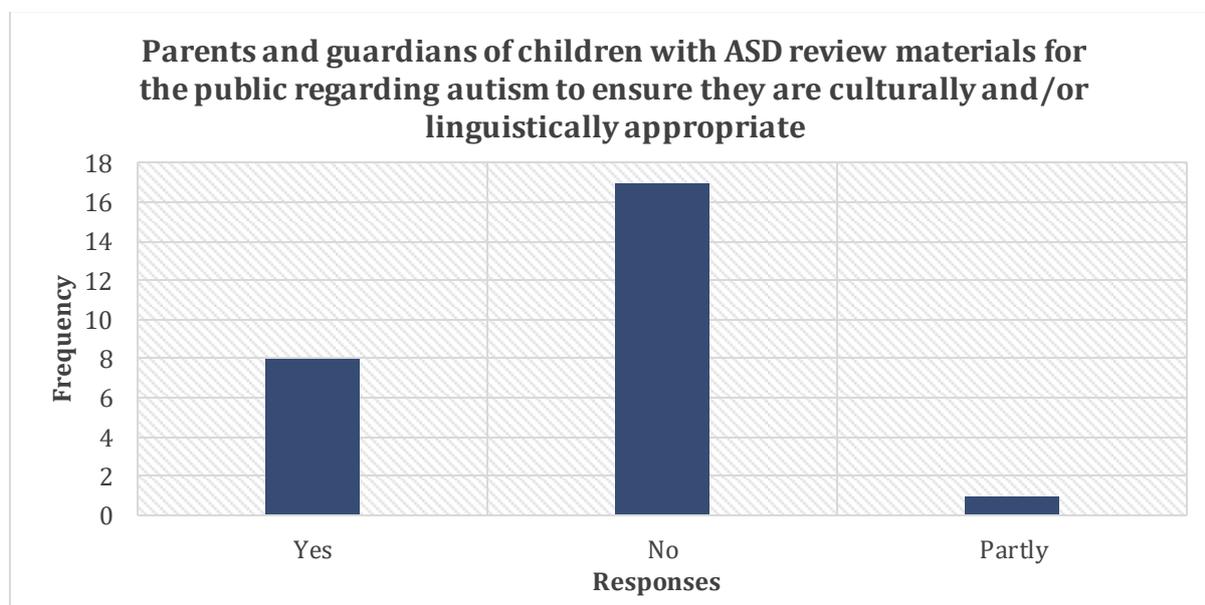


Figure 3.29: Parents and guardians of children with ASD review materials for the public regarding ASD to ensure they are culturally or linguistically appropriate

## 3.1.6. Transition to Adulthood

### 3.1.6.1. Policies or procedures to ensure continuity of care for adolescents with ASD transitioning to adult specialists and community supports

The majority of countries (n=18) did not have policies or procedures to ensure continuity of care for adolescents with ASD transitioning to adult specialists and community supports, and only eight countries reported that they did have such policies or procedures.

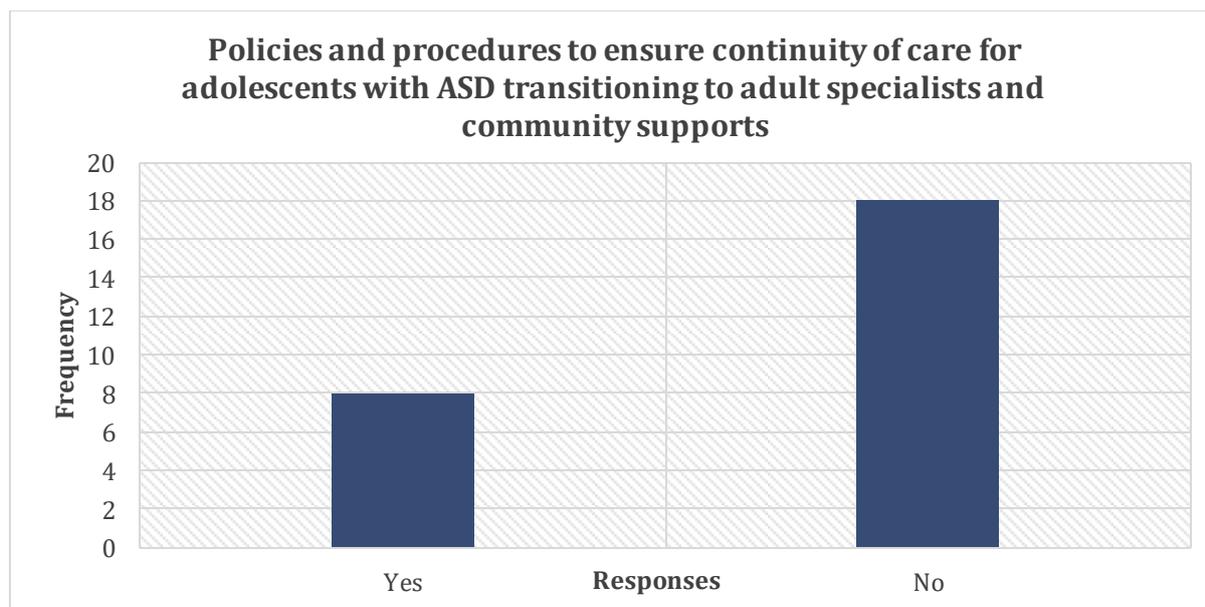
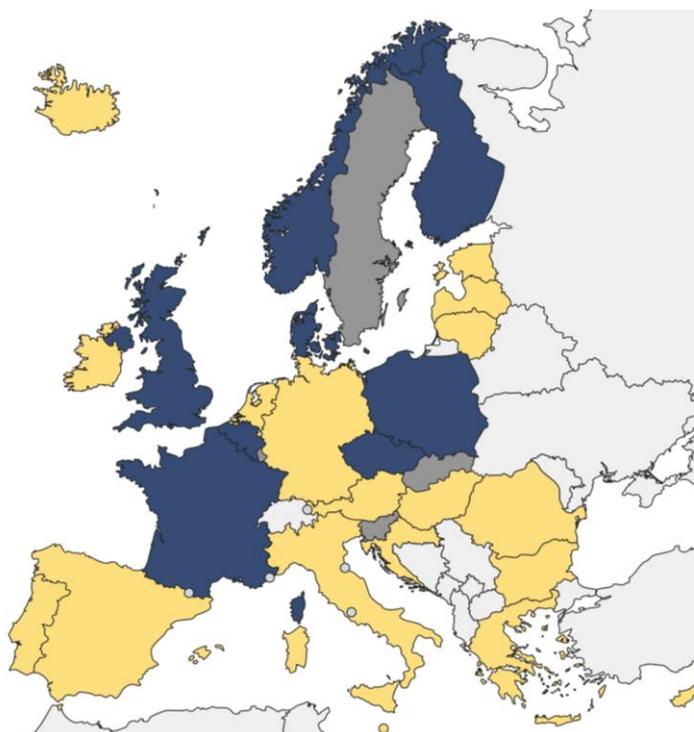


Figure 3.30: Policies or procedures to ensure continuity of care for adolescents with ASD transitioning to adult specialists and community supports

**Policies or procedures to ensure continuity of care for adolescents transitioning to adult specialists and community supports**

- Policies or procedures
- No policies or procedures
- No response
- Non-Mocha country



Map 3.7: Policies or procedures to ensure continuity of care for adolescents with autism transitioning to adult specialists and community supports

**3.1.7. Quality Assurance**

**3.1.7.1. There are quality assurance policies or procedures for service providers caring for children with ASD**

Most countries (n=14) had neither policies nor procedures regarding quality assurance for service providers caring for children with ASD. Eight countries had quality assurance policies and procedures and two countries had policies only. One country did not respond to both items.

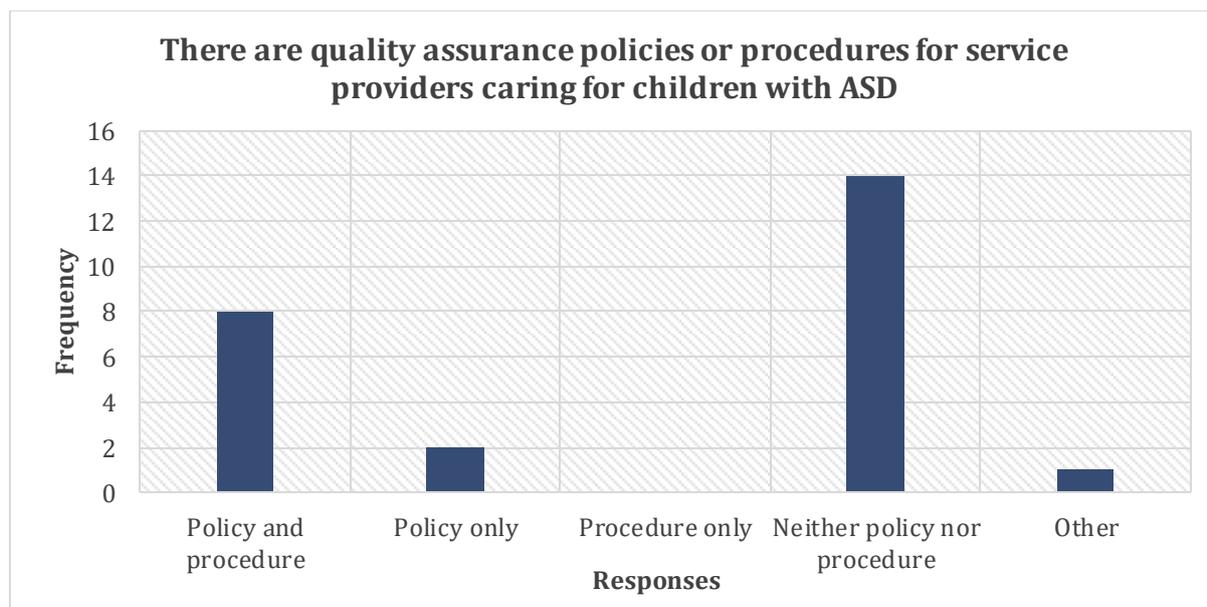
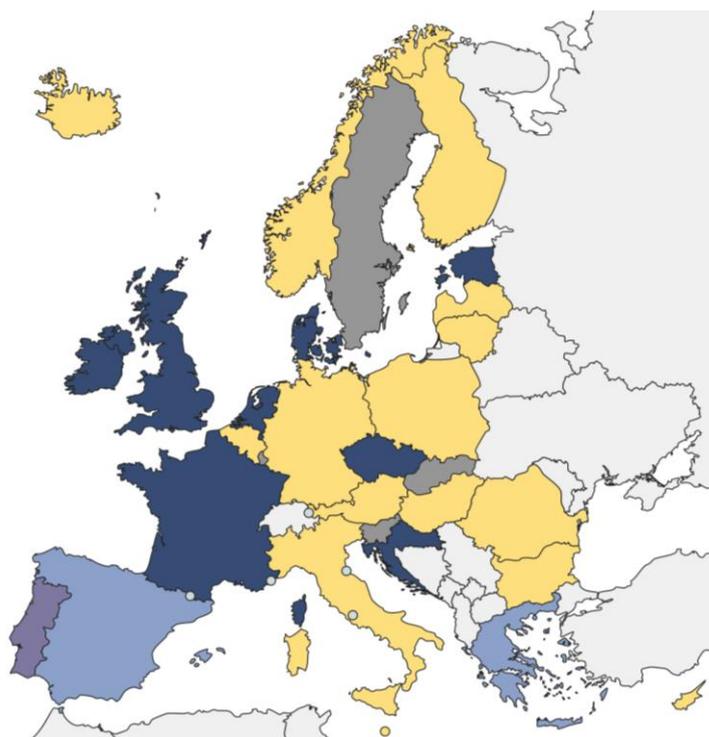


Figure 3.31: There are quality assurance policies or procedures for service providers caring for children with ASD

**There are quality assurance policies or procedures for service providers caring for children with ASD**

- Policies and procedures
- Policy only
- Neither policy nor procedure
- Other
- No response
- Non-Mocha country



Map 3.8: There are quality assurance policies or procedures for service providers caring for children with autism

**3.1.7.2. Perspectives of data collected regarding the experience of care for children with ASD**

In most countries, data regarding the experience of care for children with ASD is not collected. Of a total of 26 countries, data is collected regarding the experience of care for children with ASD from the perspective of the parents in nine countries and from the perspective of the

siblings in three countries. Primary health and social care professionals provide data regarding the experience of care for children with ASD in six countries.

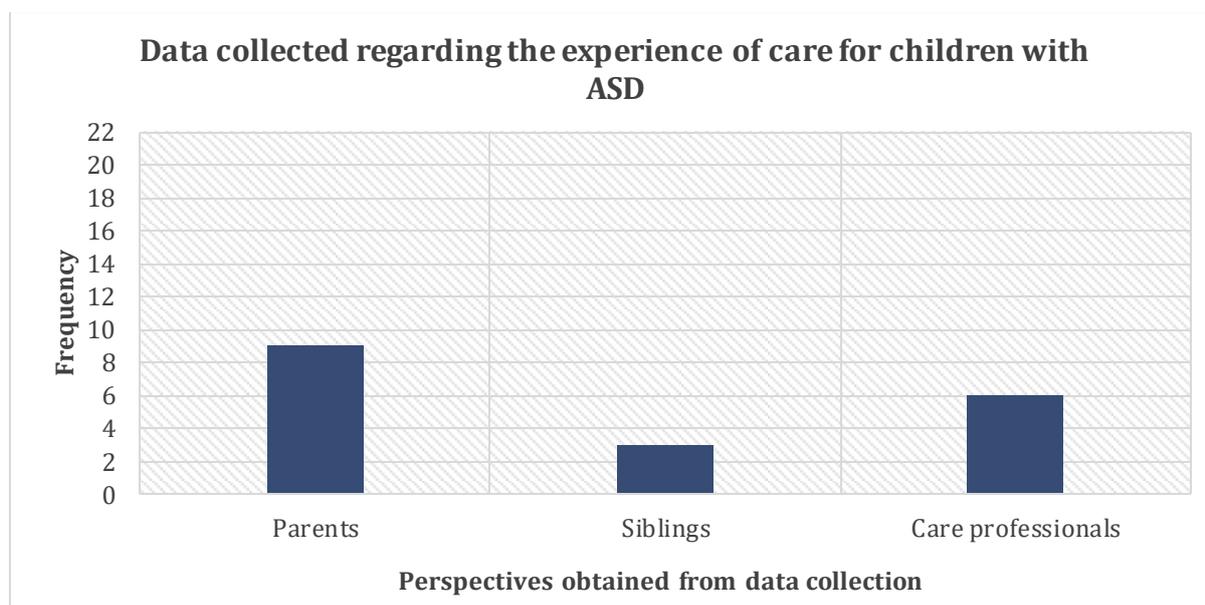


Figure 3.32: Perspectives of data collected regarding the experience of care for children with ASD

### 3.1.8. Summary of key results in the management of care of children with ASD

- More than half of responding countries reported both policies and procedures to ensure preventative care screening and developmental checks or communication of results with care providers and parents.
- A minority of countries had policies or procedures to ensure family competencies are assessed.
- Policies and procedures concerning systems to identify care providers and being treated by the same team each time were in place in more countries for healthcare than for social care.
- Less than half of countries had policies or procedures to ensure children are seen by the same team each time.
- The interface between primary, secondary and social care is not described in most countries.
- Primary care can be accessed regardless of the care given in secondary care in the vast majority of countries.
- Policies and procedures to ensure that information provided is culturally or linguistically appropriate were lacking.
- Most countries had policies to promote care coordination for children with ASD and provided a hospital discharge coordinator.
- Few countries reported having a care pathway for ASD, although the majority reported having a partial care pathway, some of which described the roles of each care provider and aimed to integrate primary and secondary care.
- More than half of countries reported policies ensuring a written personalised plan, but of these, the majority consulted with parents, healthcare and social care professionals and integrated many aspects of care. Four countries indicated that written personalised plans are commonly made for children with ASD in countries where there are no policies to enforce this.

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- More than half of countries reported that community-based services were key and that family advocacy groups made recommendations to community-based services.
- The vast majority reported that psychosocial supports for families and respite care were available and that children with ASD were offered tailored educational opportunities.
- Parents were engaged in the development of policies, procedures and national quality initiatives in the majority of countries.
- The majority of countries did not have policies or procedures to facilitate continuity in the transition to adult care.
- Policies and procedures regarding quality improvement and patient experience data were in place in a minority of countries.

## 3.2. Business Models of Care for Children with ASD

A business process model approach was used to identify the actors and collaborations who:

1. provide health and social care preventive screening and developmental checks (questions 1.2b and 1.2c)
2. develop and implement the written personalized plan (questions 3.3a-c)

### 3.2.1. Provision of preventive screening and developmental checks

#### 3.2.1.1. Use case diagram

The UML use case diagram depicted in Figure 3.33 provides a static description of the activities related to the provision of health and social screening services mirroring the relevant questions of the questionnaire.

Considering the provision of health care screening (“*Provide health care screening*” use case reported in the upper-left part of the diagram) two teams have been identified (depicted in the figure with the UML composition symbol ):

- 1) A care team composed by mental health professionals (e.g. neurologist, psychiatrist, child psychologist) (Bulgaria and Greece);
- 2) A secondary and primary care team composed of both mental health and primary care professionals (e.g. paediatrician, general practitioner) (UK).

Other actors are involved in this activity as individual professionals but not working as members of the team. In Austria, France and the Netherlands, these actors are mental health professionals. In Croatia, Hungary, Latvia, Lithuania, Malta, Portugal and Spain, primary care professionals generally evaluate the symptoms and refer the child to mental health professionals to carry out specialised screening. In Romania, a social care professional may also participate in this activity, when covered by the contract of social insurance in paediatric health services or in private health services. In Poland, the screening may be also conducted by school professionals, following a referral from primary to specialist care. In Italy, the screening is performed by the primary care paediatrician.

The same methodology has been applied for the analysis of the provision of social care screening (“*Provide social care screening*” use case lower-left part of the diagram). In this case, no team has been identified. The main actors who provide these services are social care professionals. In some countries other individual professionals are involved even if not working in a team, such as primary care (Hungary and Portugal), and school care (Croatia and Latvia).

In some countries, the provision of screening is organized in a more collaborative way represented by multidisciplinary teams composed by different combinations of mental health, primary care, social care and school care professionals.

In particular we identified:

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1. a professional collaboration among primary, secondary and social care professionals in Finland, Ireland and Norway. In the UK, Denmark and Estonia, this team composition also included school care professionals.
2. mixed teams are present in Greece and Iceland composed of mental health professionals and social workers, as well as in Belgium, where school professionals are also included and in Germany, where primary, secondary and school work in collaboration.

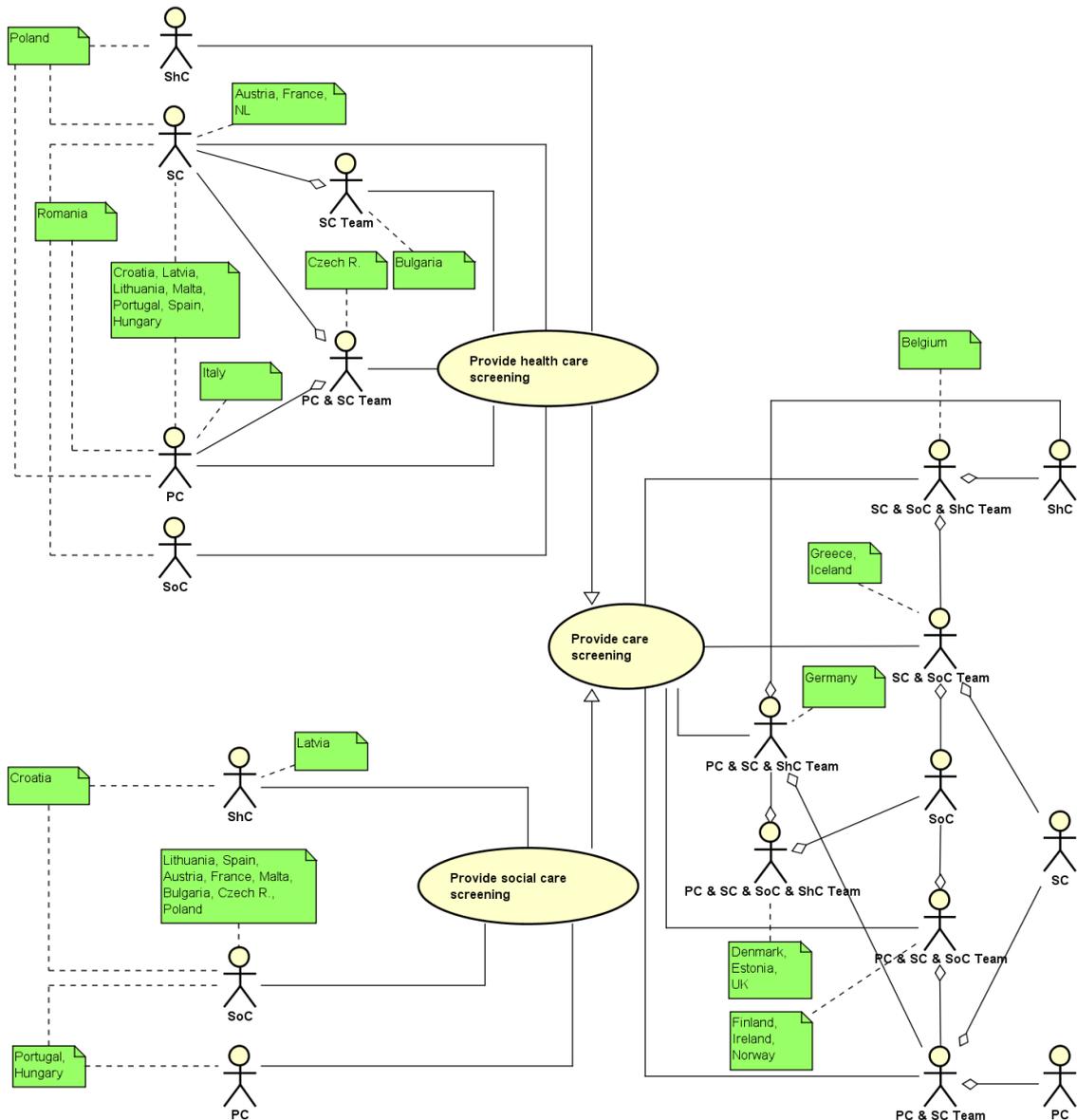
To represent this varied collaboration, a third activity (“*Provide care screening*” use case right part of the diagram) has been introduced in the model as a generalization (depicted in the figure with the UML generalization symbol  $\text{———}\triangleright$ ) of the use cases introduced above (“*Provide health care screening*” and “*Provide social care screening*”).

It is worth noting the regional variations reported by some CAs, indicating that the development of specialised centres or the introduction of an organization that tend to integrated different professionals. This is the case in Austria, where two autistic centres have been established; in France, where multidisciplinary team works in CMPP; in the Czech Republic, where a regional coordinator is foreseen to coordinate the childcare; in Tuscany, Italy; and in Catalonia.

### 3.2.1.2. Maps

A summary of the results described in the UML use case diagram is shown in the maps reported in the following figures (see Figure 3.34 for the provision of health screening and Figure 3.35 for the provision of social screening) where countries that feature professional collaboration are reported in both maps in dark blue.

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PC = Primary care professionals; SC = Secondary care; SoC = Social care; ShC = School care

Figure 3.33: UML use case diagram: provision of screening services

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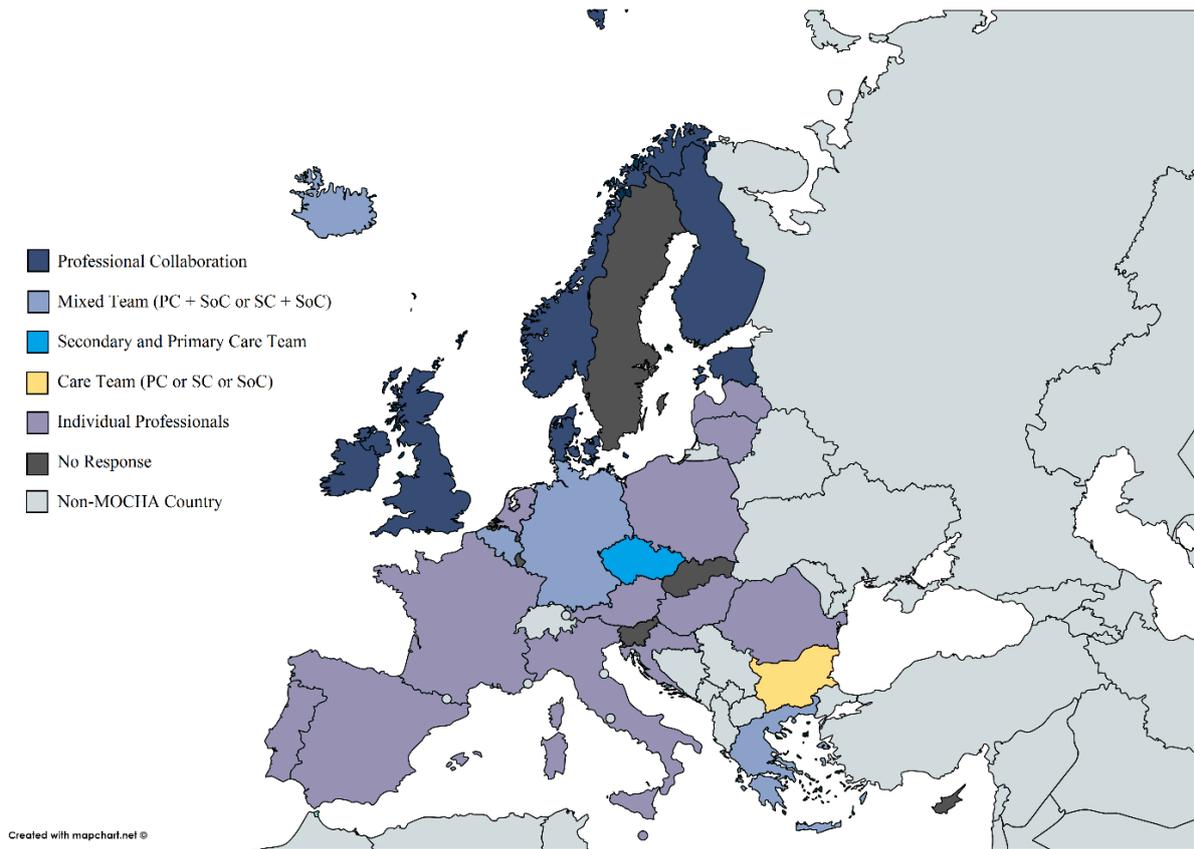


Figure 3.34: Provision of health care screening

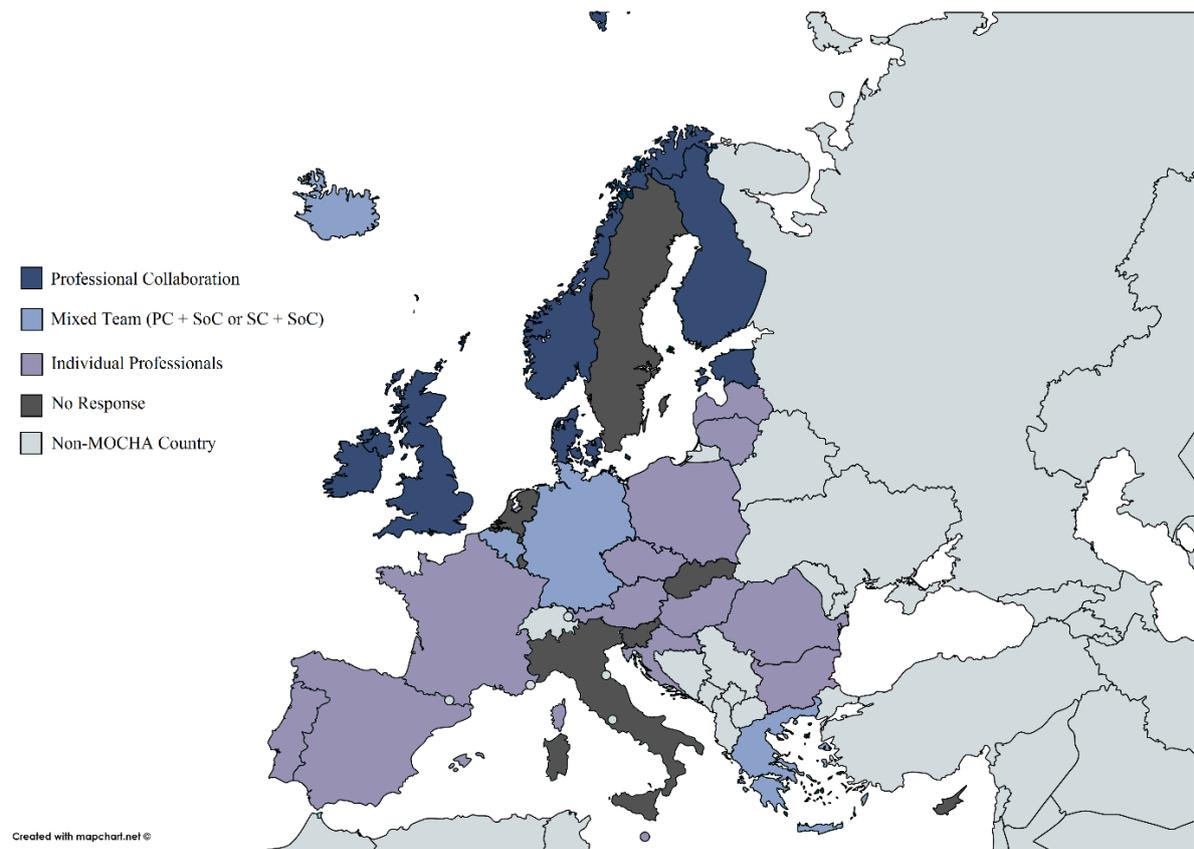


Figure 3.35: Provision of social care screening

### 3.2.2. Development and implementation of the personalised plan

#### 3.2.2.1. Use case diagram

The UML use case diagram depicted in Figure 3.36 provides a static description of the activities related to the development and the implementation of the personalized written plan. Despite of the absence of policies and procedures, some CAs reported information on the professionals involved in these activities. Therefore, the analysis below also considers these answers.

With regards to the development of the plan ("*Develop the personalized written plan*" use case), the following teams have been identified (depicted in the figure with the UML composition symbol 

1. Professional collaboration among primary, secondary and social care professionals forming multidisciplinary teams (Finland, Ireland and Norway). In Denmark and the UK, the team also includes school professionals. In particular, in the UK a special educational needs co-ordinator (SENCO) initiates and is in charge of the written personalised plan.
2. Mixed teams composed of mental health and social care professionals (Belgium, France and Greece). In Estonia, this team also comprises school professionals.
3. A secondary and primary care team composed of both mental health and primary care professionals (Czech Republic).
4. Care teams composed of mental health professionals are present in Bulgaria and Germany.

Other actors are involved in this activity as individual professionals but not working as members of the team. These actors are secondary care professionals (Iceland, Italy, Malta, Portugal, Romania and Spain). In Lithuania and Poland, primary care professionals are also involved.

Considering the implementation of the plan ("*Implement the personalized plan*" use case) a professional collaboration is present in Finland, Ireland and Norway, as well as in UK and Denmark where school professionals are also involved. Mixed teams implement the plan in Belgium, France, Greece and Estonia and other forms of collaboration are present in Bulgaria and Germany (mental health teams) and in Czech Republic (mental and primary care team).

There is variety in the type of professionals implementing the personalized plan when not organised as teams. In particular, mental health professionals are involved in Iceland, Italy, Malta, Poland, Portugal, Romania and Spain. In Lithuania, primary care professionals are also involved.

Summing up, teams responsible for both developing and implementing the plan are present in Denmark, Finland, Ireland, Norway and UK as a professional collaboration, in Belgium, France, Greece and Estonia as mixed teams, in Bulgaria and Germany as care teams as well as in Czech Republic as a secondary and primary care team.

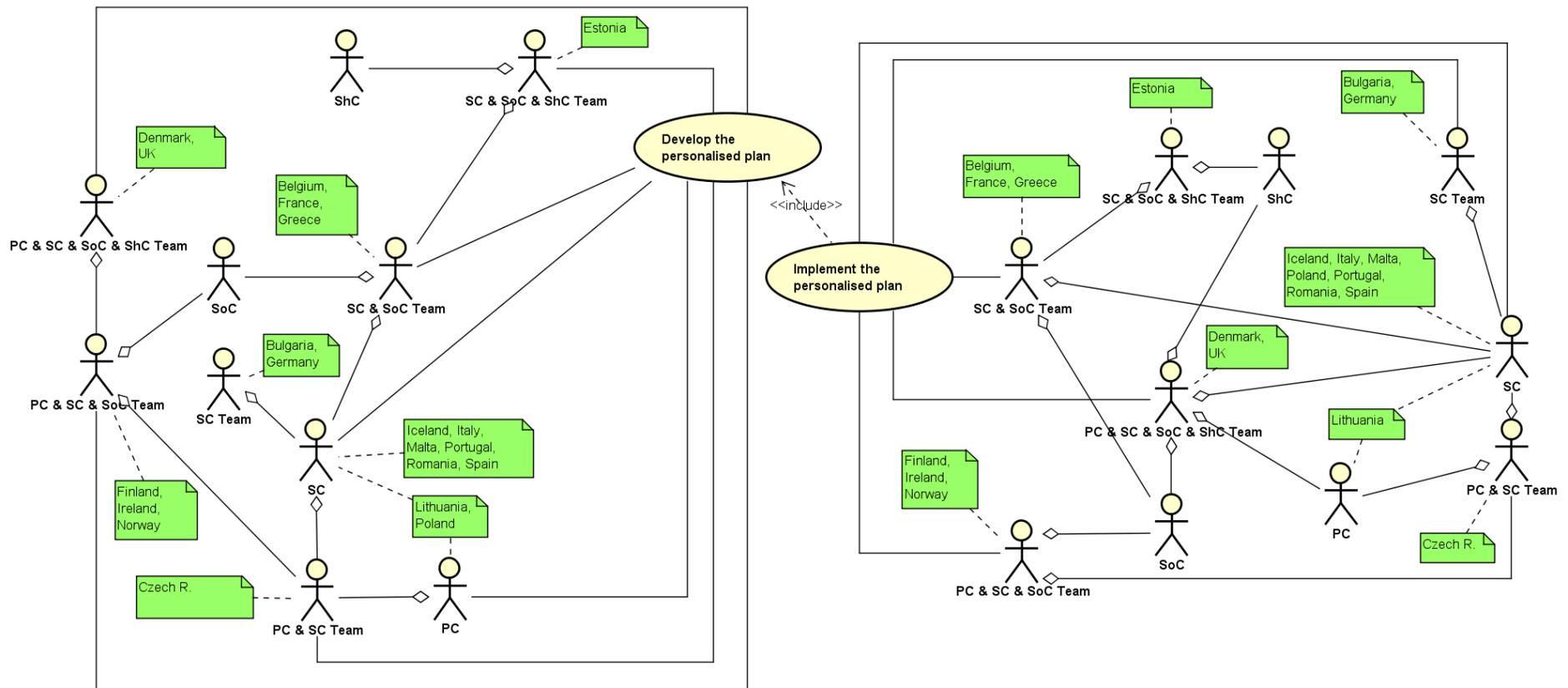
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Some CAs reported (e.g. Portugal, Romania, Spain) that there are regional differences within countries and this also influences which professionals carry out these activities. Moreover, the composition of the team may also depend on the severity of the condition and/or on pharmaceutical treatment (cf. Danish response).

### **3.2.2.2. Maps**

A summary of the results described in the previous paragraph is shown in the maps reported in the following figures (see Figure 3.37 for the development of the plan and Figure 3.38 for the implementation of the plan). Note that countries that feature professional collaboration in both activities are reported in the maps in dark blue.

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PC = Primary care professionals; SC = Secondary care; SoC = Social care; ShC = School care; MoM = member of the municipality

Figure 3.36: UML use case diagram: development and implementation of the personalised plan

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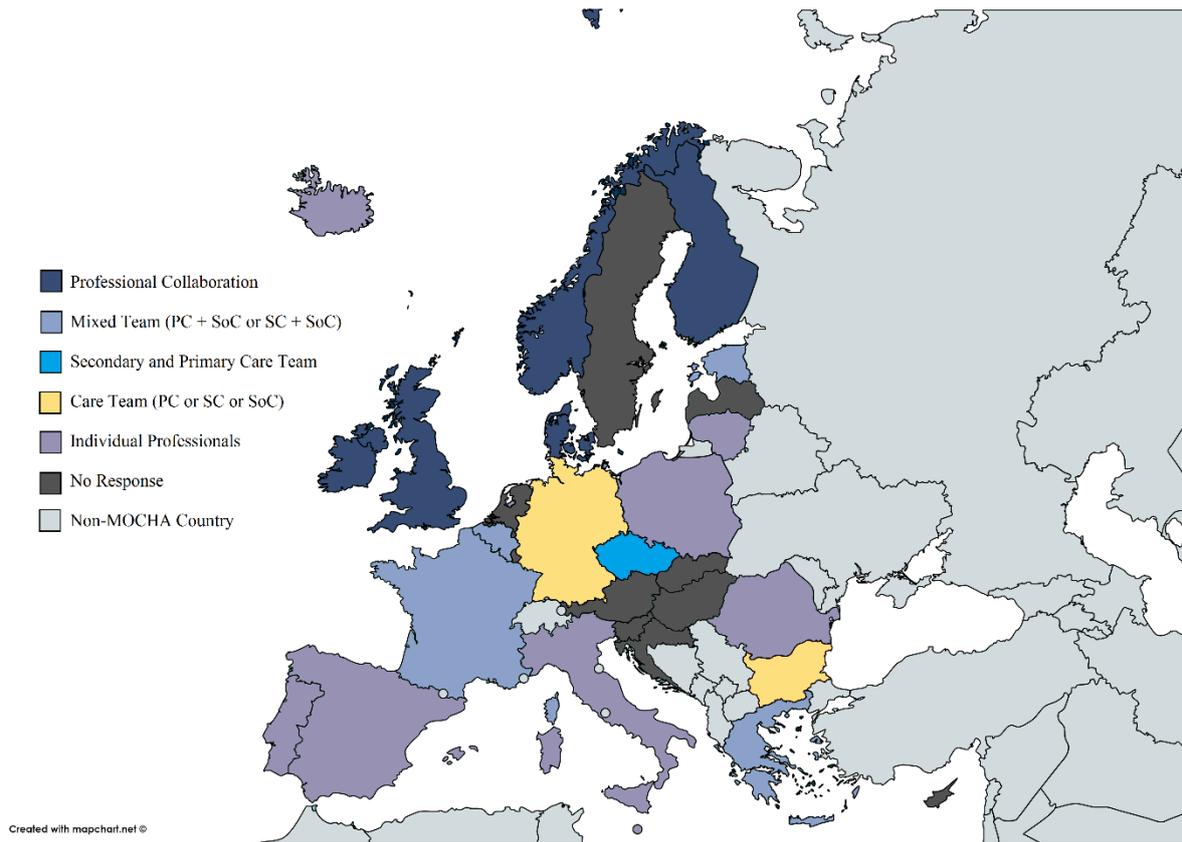


Figure 3.37: Development of the personalized plan

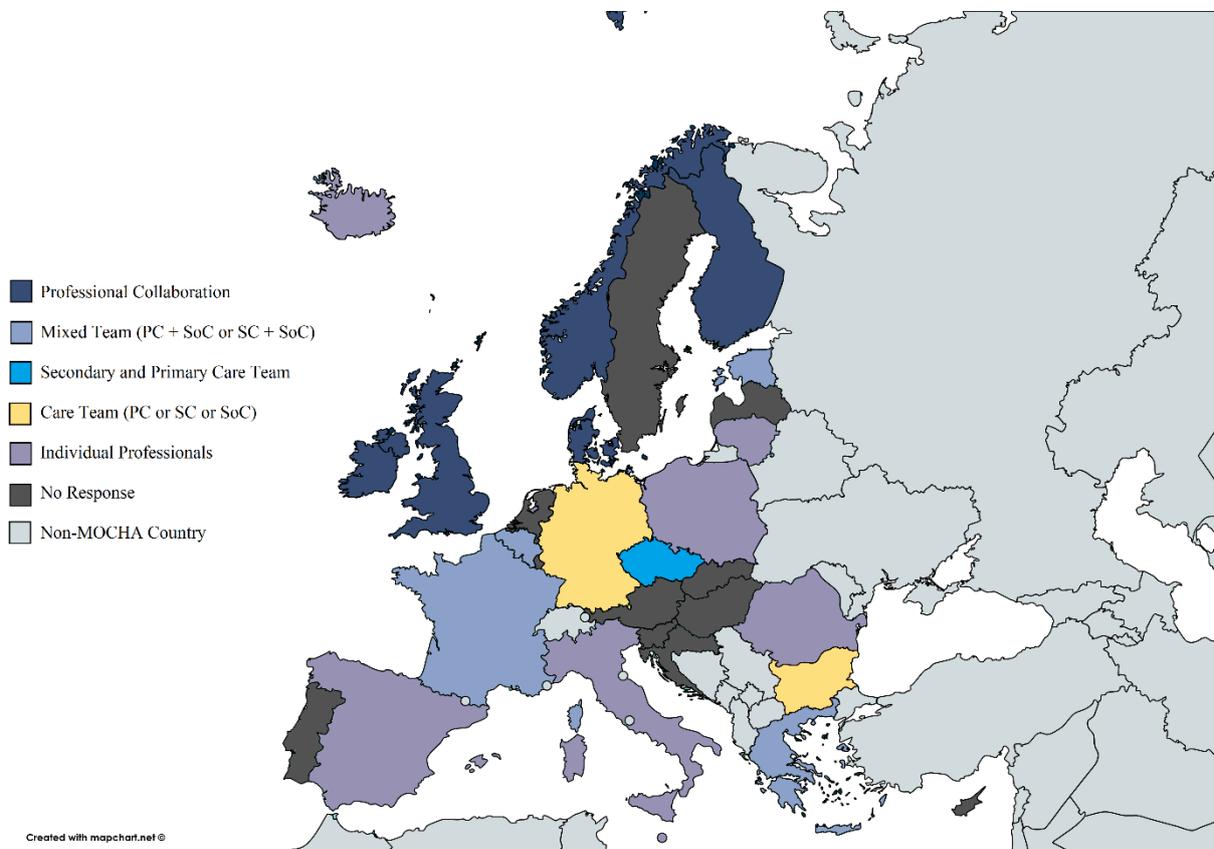


Figure 3.38: Implementation of the personalized plan

### 3.2.3. Key findings

- Half of the countries have screening activities performed by professionals working in a team with different degrees of collaboration. Among these, ten countries are organized in teams that provide both health and social screening.
- In countries where a professional collaboration or mixed team are in place, the same team is responsible for both the development and implementation of the personalized care plan. This is generally organized as part of the municipality (Scandinavian countries) or with a strong involvement of school coordination (UK).
- A team that is responsible for the whole range of activities (screening, development and implementation of the plan) is present only in countries where an *ad-hoc* service is in place (e.g. Belgium with the centre of reference for autism and Ireland with the disability team). The implementation of a shared electronic health record can help professionals stay informed about the execution of the child's pathway (see Estonia).
- Considering the social aspects of the child's care, the best pattern of collaboration includes social workers and school care professionals, but this is implemented only in a minority of countries.
- There are wide regional variations in team composition, especially when no established policies and procedures are in place.

### 3.3. Facilitators and barriers to integration of primary and secondary care

Every country in this survey recognized that ASD is a (child) mental health diagnosis that requires specialist health and social care to ensure these children receive appropriate care and treatment. A need for holistic treatment, care and support for the child and their family was described. The vast majority of European countries screen young children to ensure age-appropriate development. If the child displays signs of ASD, the child is referred to specialist professionals, such as paediatricians, neurologists or child psychiatrists, where further screening and assessment will be conducted. These tests are incorporated into general childhood development assessments where the child is screened for any physical, psychological or psychiatric issues and this occurs regardless of any pre-existing diagnoses, including ASD. The ASD diagnosis is made by specialists in the secondary healthcare system and following diagnosis, the child and their family may benefit from assistance from specialist practitioners to describe and coordinate the supports that follow.

*"After making the diagnosis, the specialised team provides the family with a comprehensive plan for further management to be led by psychologists, speech and language therapist (SALT) and special needs teachers. To reiterate, the whole process is being initiated by the paediatric psychiatrists and psychologists." (Bulgaria)*

The task of providing ongoing care is solved across healthcare, mental health and social services. Thus, the optimal model of care integrates at least those three services.

The qualitative data in this survey reveal that the optimal models of care in the EU countries involve four global themes; 1) parent involvement and coordination, 2) specialist knowledge, 3) access to specialist care, and 4) care coordination.

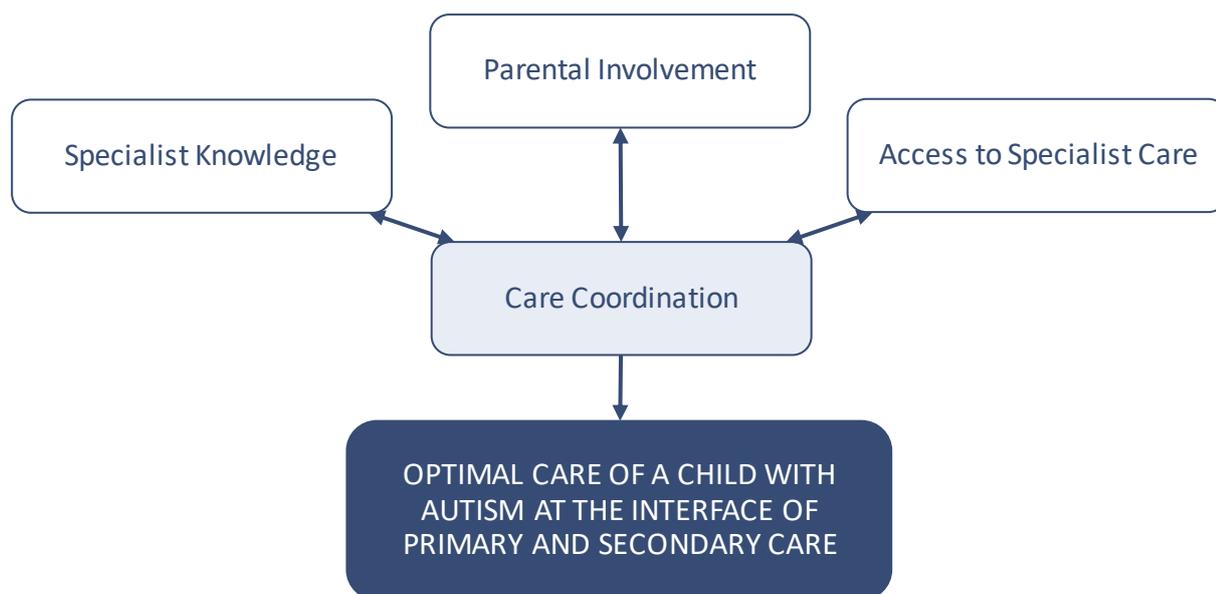


Figure 3.39: Global themes in context

### 3.3.1. Specialist knowledge

This global theme describes what affects the level of specialist knowledge and emerged from the professional perspective, rather than the patient perspective. Knowledge about ASD is a key factor for diagnostics and for ensuring appropriate ongoing care after a child has been diagnosed. The Country Agents commonly acknowledged the need for specialist knowledge in this regard and there seems to be a lack of specialists in primary care and the social care system, in particular. The emergence of specialist knowledge as a global theme is based on the degree of the specialisation and the way that professional expertise is organised. The specialist level is on one hand defined by the existence of specialisation and on the other hand defined by the way this specialisation is put in use.

#### 3.3.1.1. Degree of specialisation

The degree of specialisation refers to the standard of specialist training and skills of the professionals caring for autistic children and the extent to which care is delivered in the secondary and tertiary care systems.

##### **Knowledge gaps**

Significant gaps in knowledge and a need for specialist expertise were identified by the respondents. The majority of countries stated that the optimal priority of ensuring the care for autistic children happens through integration of political, organisational and professional knowledge, as the appropriate degree of knowledge is defined in the daily practice of the professionals and everyday life in the families, but the resources have to be allocated from the political level.

##### **Political awareness**

The degree of specialisation is shaped by awareness at the political, parental and professional levels of the need for special intervention. Primary and secondary healthcare professionals and parents' associations can inform the political system of knowledge gaps and existing levels of expertise.

##### **ASD associations**

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ASD organisations and parents' associations, who have the greatest expertise regarding the daily care needs for autistic children, provide a unique perspective and important contributions to political awareness. The ASD associations are by most countries described as very strong organisations with substantial influence at the national and regional decision-making level.

### **Availability of specialists**

Most countries described a lack of specialists, and consequently a lack of specialist knowledge, as a challenge to care provision. The degree of specialisation around which the healthcare system is organised has some influence on the supply, via education and training, and demand for specialists.

*“More community-based services are needed in order to provide suitable care for children with autism. Additionally, healthcare providers with specific knowledge under the spectrum of autism are required for the optimal care of children with autism.” (Cyprus)*

### **Primary, secondary and tertiary care**

ASD is recognised as a diagnosis that requires specialist care and as a result, primary care routinely involves secondary and tertiary care. Some responses suggested that an increasing degree of specialisation in the national healthcare and social care systems facilitates more formal care pathways, leading to easier access to referrals to specialist collaborators. Some Country Agents described the regional differences in the structure of the professional expertise to affect the level of specialist knowledge because the higher degree of specialisation, the lower degree of collaboration. As a result, specialist knowledge is not shared, which affects the primary level of knowledge about ASD.

*“The so called expert centres for children with disabilities and chronic diseases are being created and these are endorsed by the new medical standard (Guideline in Paediatrics) approved with Regulation [...]. These will be expected to provide all kind of care – from diagnosis to rehabilitation, parent education, and social services under one roof.” (Bulgaria)*

### **3.3.1.2. Structure of professional expertise**

The structure of professional expertise affects the level and specialisation in general in a country. The activation of different specialised care services indicates the need for a certain level of expertise, and thus the structure of expertise will reveal the map of the necessary care services.

### **Screening and assessment**

The Country Agents reported that they have the specialist knowledge to perform screening and assessment. The screening occurs mainly in regard to developmental check-ups and is performed in primary care. If there are concerns regarding ASD, most countries are referring to secondary care for assessment. This division between caregivers increases responsibility at the different the specialist levels and consequently affects the level of specialist knowledge.

*“The process is usually started by the municipal children’s health care centres or day care, where the university educated day care nurses suggest the parents to contact medical team, for getting diagnosis and plan for rehabilitation.” (Finland)*

### **Individual care plans**

The individual care plans affect the level of specialist knowledge as they describe the care needs at the clinical level. Thus, care needs that are not met will increase the demand of specialist knowledge.

*“There are not enough public services specialized and tailored to their specific needs. There is rarely a care plan coordinated by a case manager. Specialized care centres usually work with a care plan, but there are few such centres.” (Romania)*

### Stepped care

Most countries utilise a stepped care approach, where the assessment leads to a referral to a specialist service if the care needs are not met at the primary care level. Knowledge on when, how and to whom to refer a child with ASD is a highly influential factor to ensure that the child is cared for by the most qualified care provider in a continuum of care. Countries with a spectrum of specialized units involved in a stepped care approach reported being satisfied with the national care service, suggesting that the role of gatekeepers in primary care referring children to specialists may be a key factor regardless of whether the specialists are placed in primary or secondary care.

If stepped care is not used, the professionals may under- or over-estimate the care needs, which aside from being an inexpedient use of resources, also may cloud or even hinder the flow of specialist knowledge. Without an overview of the organisation of the knowledge base, the existing expertise becomes invisible and under-utilised. Ultimately, the development of specialist knowledge will be influenced by an inter-professional structure, rather than the care needs of children on the autistic spectrum.

*“This regards all health care providers that you can access without a referral from another health professional. These include the general practitioner, physical therapist, social worker, dentist, and pharmacist. Among these providers, GPs have a key role. A specialist in a hospital or a psychologist can only be visited after a referral from for example a general practitioner. Therefore that is not listed as general health care services, but as specialized health care services.” (the Netherlands)*

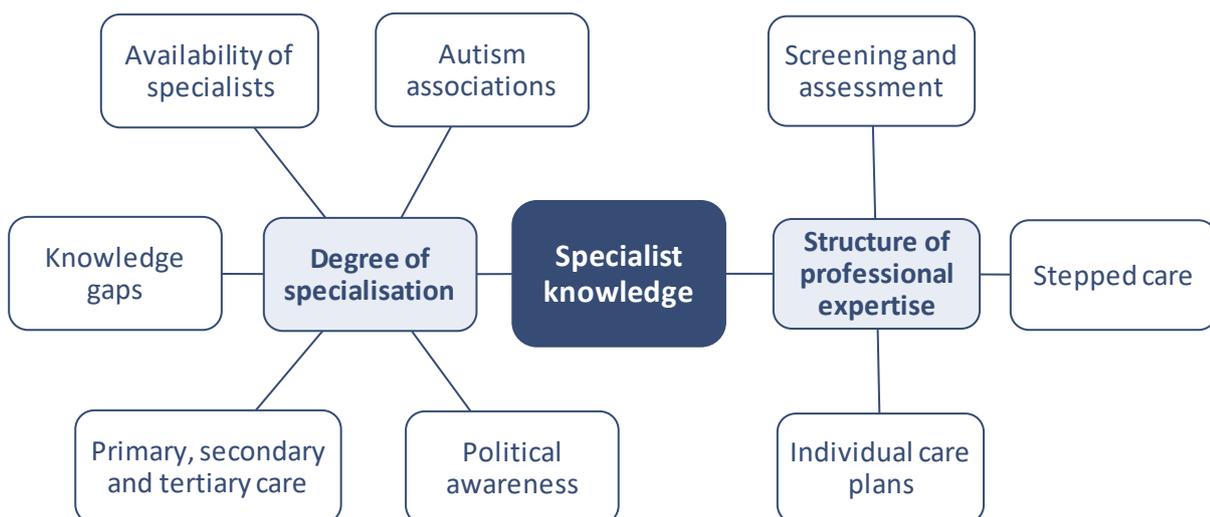


Figure 3.40: Emergence of Global Theme “Specialist knowledge”

### 3.3.2. Access to specialist care

Meeting the special care needs of a child with ASD requires a range of different professionals. This theme is coherent with the above-mentioned level of specialist knowledge, but emphasises the accessibility of the care seen from the patient and family's point of view and not just whether the specialist knowledge exists.

#### 3.3.2.1. Organisational access to care

##### **National regulation**

Respondents reported that care provision for children with ASD was regulated at either a national or regional level. Countries that lacked comprehensive national policies reported regional heterogeneity, which was cited as a challenge in terms of ensuring access to care in all locations. Those differences were mainly a result of not having national regulation and thus the guidelines were decentralised to the regional level. This creates an inequity in terms of access to services, which is determined by location as opposed to need.

*“Due to the “relative small volume” of affected population mechanisms in place assure reasonable level of care services in all needed areas, work is being done (under governmental auspices) to assure a higher level of standardization and integration in order to assure universal access to high quality services irrespective of geographical locality.” (Czech Republic)*

##### **Regional differences**

Several countries stressed that they had significant regional differences in specialist services. As stressed by one Country Agent, differences between regional services does not necessarily mean substandard care, and some Country Agents stated that the local organisation and structure are more important when ensuring organisational access to care.

*“The guidelines so far are not ‘National Level’ but rather ‘Regional Level’ documents, since the respective Regional Coordinator for the care of children, pupils and students with ASD addresses and maps and uses only the existing regional infrastructure.” (Czech Republic)*

##### **Gatekeepers**

The function of the gatekeeper was described as crucial when ensuring access to different care units and specialists. This may be between primary and secondary care, between sectors or between key specialists within the same sector or level of care provision. The role of gatekeepers determines the access for a child with ASD to access services especially in secondary care, when most countries stated that the care for children with autism should be situated. Primary care is also seen to have a function in providing access both into social care and in collaboration with social care. Gatekeepers are therefore important facilitators to accessing other services when utilising a stepped care approach.

*“Primary care is always accessible for a child, no matter what kind of secondary care is provided. However, primary care acts as a gatekeeper for secondary care. Only if you get a referral from a primary care giver, you can access secondary care.” (The Netherlands)*

##### **Multidisciplinary teams**

Many countries stated that multidisciplinary teams are an important factor for ensuring access to appropriate clinicians. Multidisciplinary teams seem to increase the availability of specialists for ASD, particularly when care guidelines specify which type of specialist professional is responsible for

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delivering care. Tertiary care services, such as specialist ASD centres, may facilitate effective integration of multidisciplinary teams, for example to a question regarding which professionals care for children on the autistic spectrum:

*“If the child is in the programme of an Autism Competence Centre or in the programme of the Autistenhilfe (autism support) or not. If it is, these centres will be in charge of all relevant problems. Otherwise for all other conditions the child will be treated by the family doctor or by the family paediatrician” (Austria)*

### **3.3.2.2. Funding**

#### ***System resources***

In nearly all countries, funding of care was found to be of very high importance. Most countries stated that they lacked resources, which is a barrier to improving service provision for children with ASD. A shortage of funds reduces the available specialists and puts great demands on the families with children with ASD.

*“There are no specialised social care workers for children with autism. Children with autism receive a monthly financial support and the family seeks for services either in the public or in the private sector on its own.” (Cyprus)*

#### ***Political will***

Several country agents stated that this was a result of lacking priority by the national political level. In general, countries reported that more political awareness about ASD resulted in more resources being allocated to services for autistic children, and thus increased access to specialists.

*“Firstly, an important barrier is lack of legislative correctness of enacted law, which considerably hinders autistic children’s access to health care. Secondly, there are not enough funds for proper care of children with autism.” (Poland)*

#### ***Fee-based care***

The accessibility to care is under influence by the economic element of fee-based care. Needless to say, the higher degree of self-financing the higher barrier in associability to care, and in particular in low-income families.

*“The economic status of the family plays a major role for the care of a child with autism. The state provides monthly sponsorship, according to the financial status of the family, for caring a child with autism but it is usually not enough to provide the appropriate care.” (Cypress)*

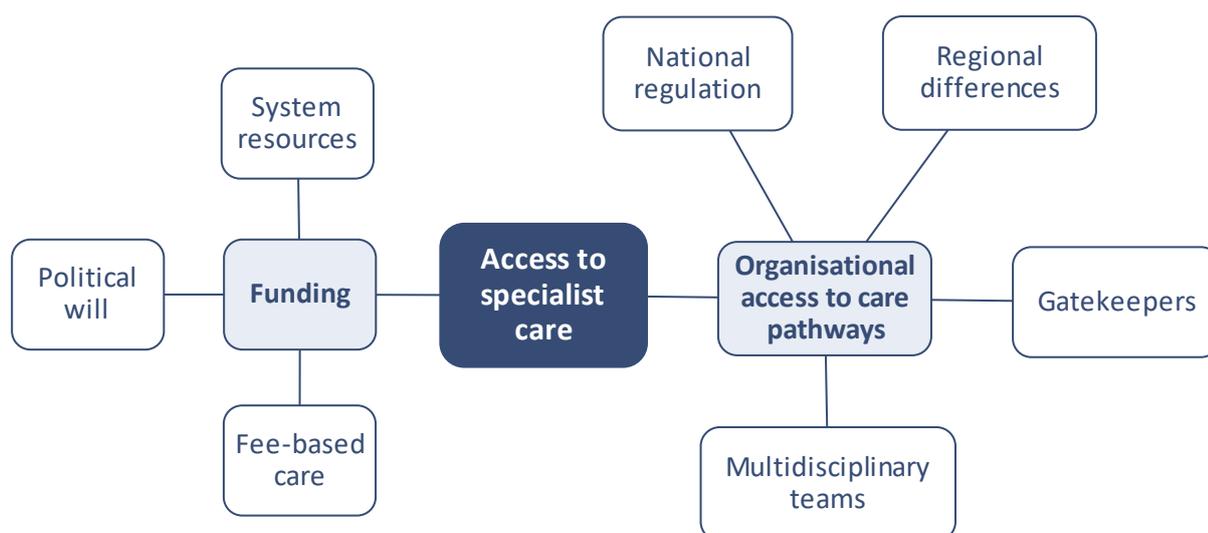


Figure 3.41: Emergence of Global Theme “Access to specialist care”

### 3.3.3. Parental involvement

The role of the parents<sup>2</sup> is an important part of providing care for children with ASD as parents are the main care providers and the experts on their child’s care needs. Unsurprisingly, every country reported that they cooperate with the parents.

*“The main actors in care of children with ASD were, and still are, the parents and family members who are fighting for their child’s right to get the necessary care and education.”  
(Estonia)*

Most of the countries stated that an integrated part of the care of the child must include providing support to the parents and families when a child is diagnosed. Respondents indicated that parents often act as the “help-seeker” who initiates assessment and later as the coordinator, arranging the various elements of the diagnostic process, as well as ongoing care after the diagnosis has been made. The parent becomes responsible for specific tasks relating to the child’s care, such as coordinating appointments and accessing services, as well as the everyday parenting of the child.

*“The care for children with autism very strongly depends on the parents’ desires, work and determination.” (Lithuania)*

The knowledge of the families is taken into account when creating the overall descriptions of the care needs of children with ASD and parents’ associations play an important role in supporting parents and

<sup>2</sup> In absence of a commonly used definition of parents, the term “parent” in this report is defined as “Any person who, although not a natural parent, has parental responsibility for a child or young person” (Section 576 of the Education Act 1996, UK). Parental responsibility is defined as “assuming all the rights, duties, powers, responsibilities and authority that a parent of a child has by law” (The Children Act 1989, UK).

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devising national approaches to care. Country Agents from Scandinavian countries in particular reported that the voices of parents' associations are incorporated into the political agenda.

*“Parents' associations are doing a great job, especially regarding coaching and (teaching) the parents how to handle the problems they are experiencing with their child's autism. Courses for parents, networking, seminars, etc. are being offered. It is often the parents themselves who is responsible for coordinating these activities.” (Denmark)*

*“Autism society in Norway has been important in development of services and knowledge about autism.” (Norway)*

Parents of autistic children are often responsible for securing assessment and ongoing care for their child. They also have a special knowledge that may not exist elsewhere and may be considered a key resource as they provide important information to the healthcare and social care systems to ensure their child receives adequate care.

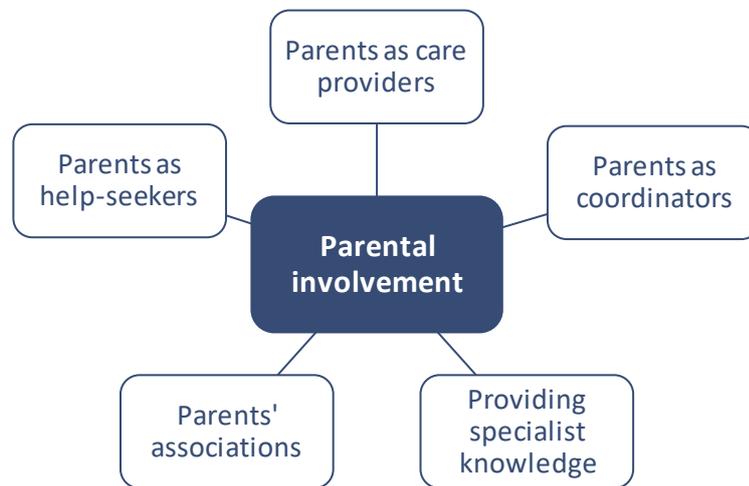


Figure 3.42: Emergence of the Global Theme “Parental involvement”

### 3.3.4. Care coordination

Care coordination as a Global Theme emerged from two Organising Themes, where “communication” and “integration of services” are in place to ensure that optimal care is provided (see Figure 3.44). The other three Global Themes (specialist knowledge, parent involvement and access to specialist care) all influence and are influenced by the fourth Global Theme, “coordination of care” (see Figure 3.39).

#### 3.3.4.1. Communication

Respondents indicated that the clarification of roles and responsibilities are particularly important when establishing care for children on the autistic spectrum whose needs are being met by multiple sectors. In particular, health and social care professionals stressed the need for a clarification of the areas of responsibility. Roles and responsibilities in care are closely linked to the individual care plans. Country Agents stated that the written care plan both legally and functionally secures care across a wide range of professionals and sectors.

#### Healthcare providers included in responses for autism:

- Child neuropsychiatrists
- Neurologists
- Child and adolescent Psychiatrists
- Paediatricians
- General practitioners
- Specialised nurses
- Public Health nurses
- School nurses
- Psychologists
- psychotherapist
- Orthopedagogues
- Speech therapists
- Occupational therapists
- Music therapists
- Health visitors
- Social workers
- Pedagogues
- School teachers

Figure 3.43: Healthcare providers included in responses

The majority of the countries stated that they involve and inform the families as much as needed, but very few of the countries systematically ensure that they communicate in a linguistically and culturally appropriate manner.

*“No general guidelines but there is awareness on speaking in a language that is understandable, and the family is encouraged to bring a support person if there are some conditions in the family that make it difficult to understand the information.” (The Netherlands)*

#### 3.3.4.2. Integration of services

Integration in cross-sectoral pathways is mentioned by several countries as having a high impact on the delivery of care across the care continuum. Children with ASD have cross-sectoral care needs that shift according to different phases of life, and as a result, they benefit hugely from integrated care, especially at transitional periods such as the transitions from child to adolescent to adult care. Few respondents referred to legislation regulating for example transition to adult services, which aims to precipitate seamless care:

*“In order to serve the young person with autism, social and medical services can be offered jointly (integrated) with vocational training and employment services, to as well as with other necessary services (The Governmental Order/2016 with Methodological Norms and its attachment for implementing Law 151/2010, Article 7, paragraph 7,8, 9).” (Romania)*

A few countries describe how tertiary care is integrated in either paediatric or adult mental health services. Such integration would help the transition and ensure continuity.

*“Autism Competence Centres offer care, treatment and therapy/interventions as well for children as for adolescents and adults.” (Austria)*

Nevertheless, most countries reported that there is a need for a higher degree of integration of services for children with ASD to ensure an adequate care coordination.

*“All children under the age of 18 are under the protection of the Greek state and Law, and their families are responsible for caring for them. Once they reach their 18th year of age and are considered adults, it is not the responsibility of the state to cater for their continuing care.” (Greece)*

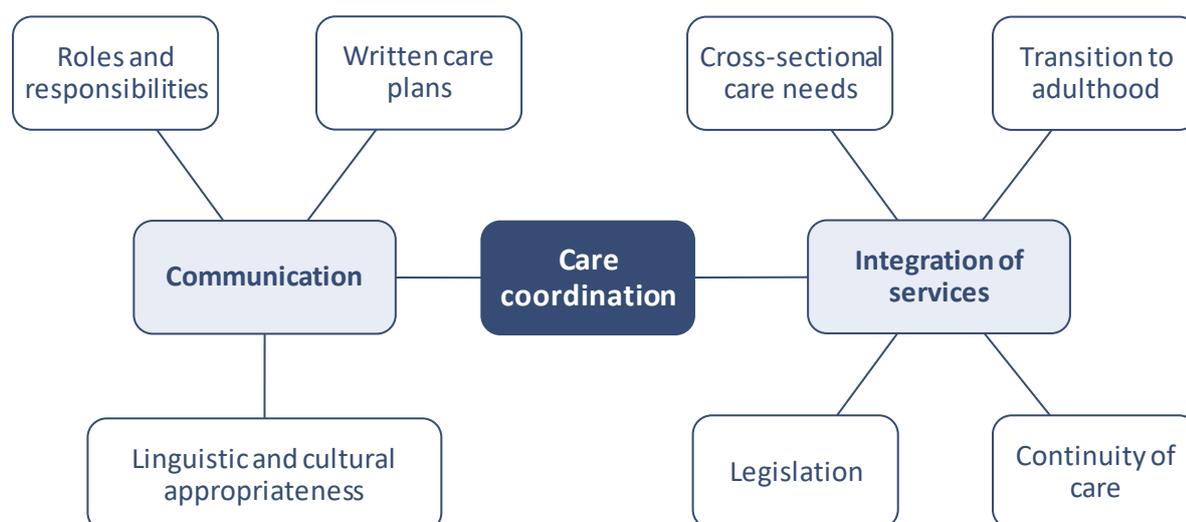


Figure 3.44: Emergence of the Global Theme “Care coordination”

Overall, optimal care for children with ASD begins with knowledge and awareness of their care needs. This knowledge is highly influenced by collaboration with the families. It is equally important to ensure easy access to specialist care in healthcare and social care units. If the level of expertise in primary care is adequate and there are sufficient specialist units in the secondary and tertiary care systems, a stepped care approach can be used to benefit each individual’s particular and shifting care needs. Thus, knowledge and easy access to specialized, family-centred, multi-agency care must be coordinated. Achievement of this coordination mainly depends on the level of communication and integration of services. It is important to stress that the four emergent themes entwine as none of the themes can be considered an optimal care model for children with ASD.

### 3.3.5. Summary of optimum integration of care at the interface of primary and secondary care for a child on the autistic spectrum

- Parental involvement is crucial for coordination of treatment and care
- ASD is recognised as requiring special care and treatment, which calls for a certain level of specialist knowledge
- Multi-disciplinary teams are important factor in ensuring access to care
- Due to the special care needs of children on the autistic spectrum, a specialist job for primary care is assurance of referral and coordination

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- Communication between various care providers, ideally through written care plans, is crucial
- Access to secondary and tertiary care is secured via primary care
- Funding at several levels highly affects access to care
- The engagement of social care, school and municipality ensured better care coordination between sectors and caregivers
- Transition between services, including transition into adult services, compromises continuity due to lack of cross-sectoral and cross-professional alignment
- National and regional legislation highly influences on available care services

### 3.4. Survey of Change in the care of children with ASD

The Survey of Change section of the questionnaire concerned opportunities and barriers for integration of care, public awareness and the political climate with regards to care for ADHD and ASD, with a focus on changes in recent years.

#### 3.4.1. Overall integration of care for children with ASD during the last five years

Figure 3.45 shows that of the 26 countries that responded 18 of them stated that the integration of care has improved. Six countries suggested that the integration of care has stayed the same and two reported that the situation in their country had declined.

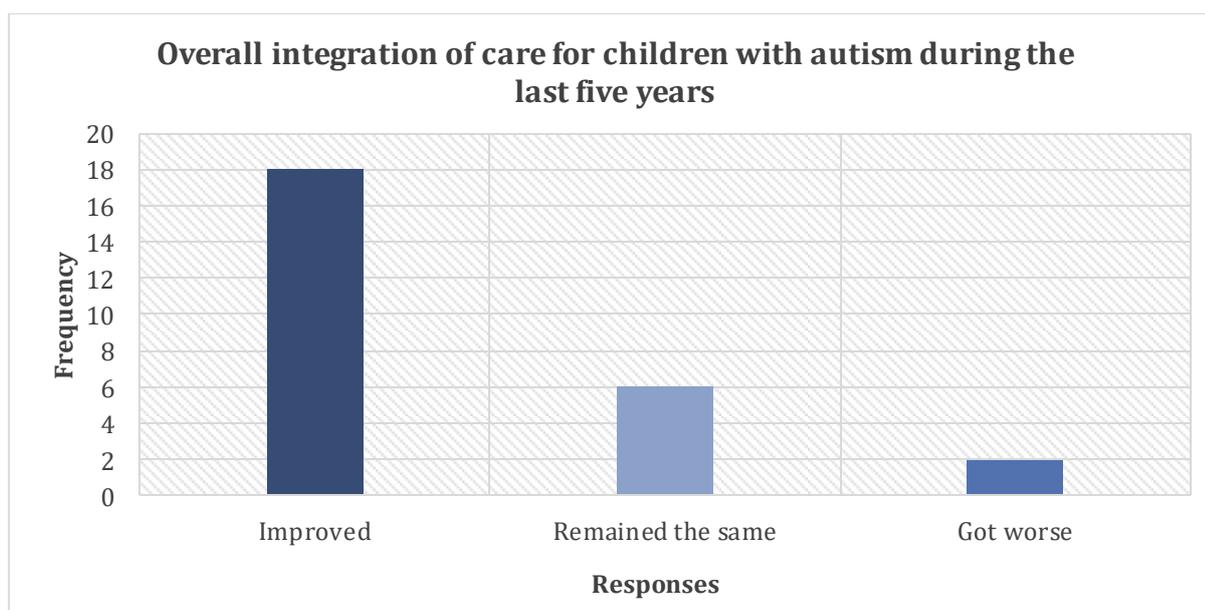


Figure 3.45: Change in the integration of care for children with ASD

The majority of the countries (n=18) stated that the integration of care improved over the past five years. The factors described as the most influential included political and public awareness, health policies and standards, the level of specialist knowledge and coordination between care services.

While six countries reported that the integration of care for children with ASD stayed the same, it is not known whether this stasis was beneficial for the quality of care for autistic children. All of the countries implied that integration of care remained the same due to the level of national and governmental involvement and priority.

The decline in the integration of care reported by two countries was explained by responsibility for care being shifted away from healthcare towards community-based care and a drive to absorb the autistic children into the existing educational system, where knowledge regarding ASD was lacking. The two countries also stated that this shift was caused by a lack of funding.

Country Agents commented on the current stage of integration of services for autistic children with regards to political awareness strategies, EU involvement and funding and resources. The feedback from each of the Country Agents indicated that there was a dichotomy across the different countries with regard to service integration and that the countries that experienced improvements in funding

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and policy development were also the same countries who reported improved public awareness and professional relationships.

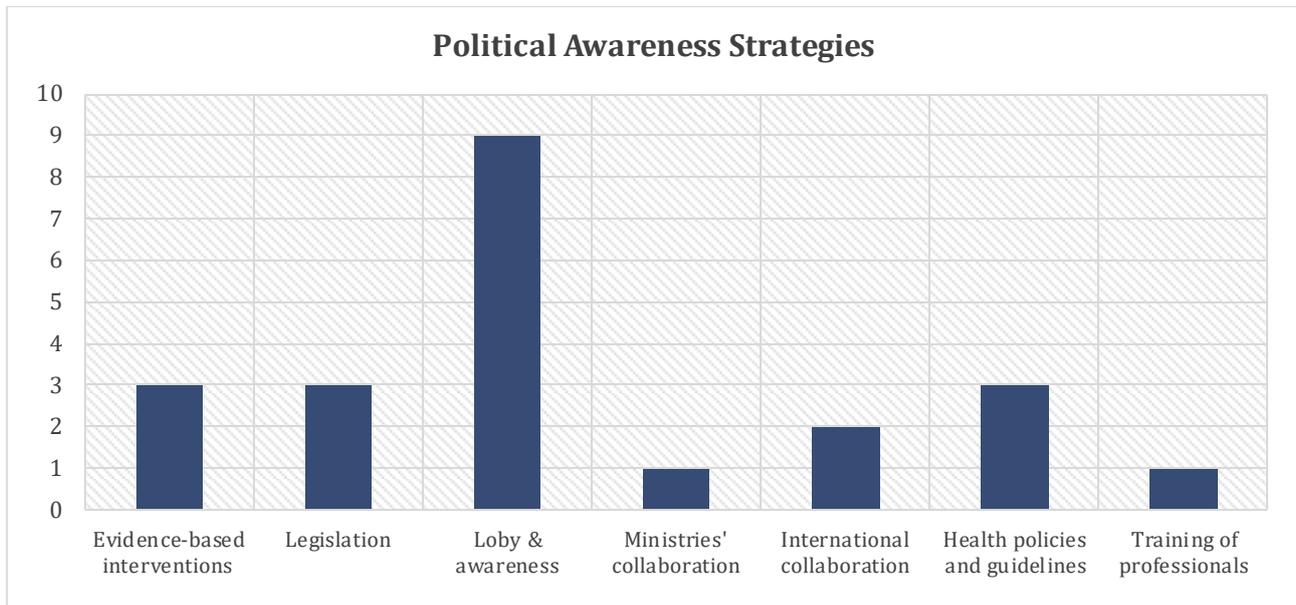


Figure 3.46: Political awareness strategies reported

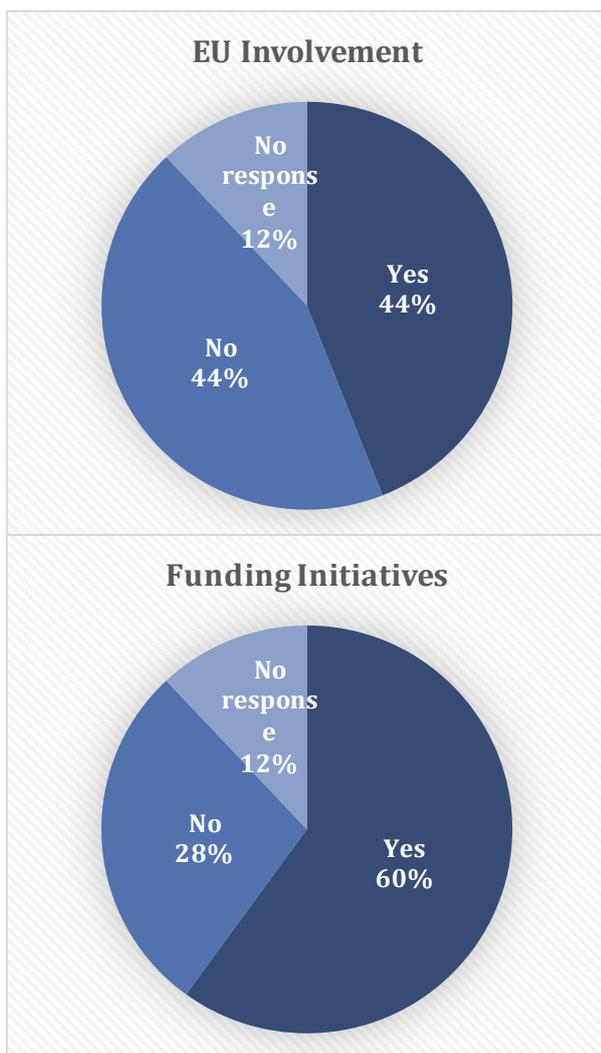


Figure 3.47: EU involvement reported as factor influencing care integration

Figure 3.48: Funding initiatives reported as factor influencing care integration

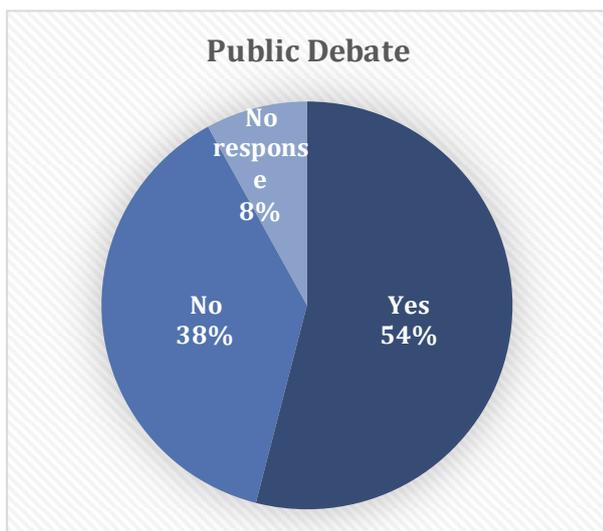


Figure 3.49: Public debate reported as factor influencing care integration

### 3.4.2. Main barriers and opportunities

Analysis of the feedback provided in regard to the main barriers and opportunities the Survey for Change identified a number of key themes: policies and standards, resources, professional coordination, and awareness and advocacy. The themes were evident both in the reports of countries who had implemented these improvements and in the reports of those who were less established in developing integrative care and services. Overall, there seems to be a tendency towards improvements in integrated care and service delivery for children with ASD.

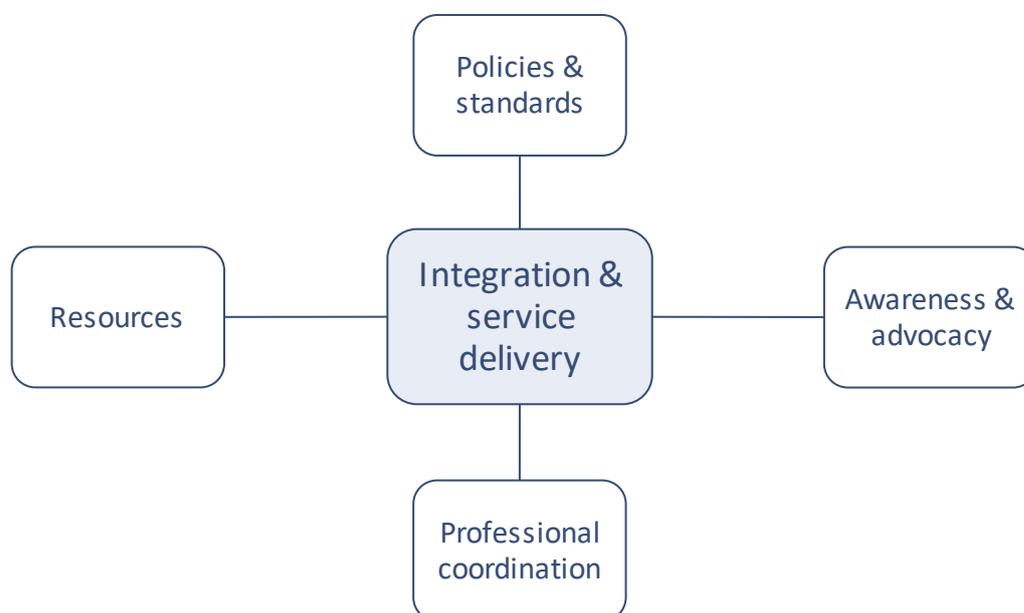


Figure 3.50: Thematic network emerging from the Survey of Change regarding integrated care for ASD

### 3.4.3. Policies and standards

Many of the key variables regarding policy and standards are shown in Figure 3.46, which displays the political awareness strategies cited by Country Agents. A principal theme is the importance of national health policies and guidelines for diagnosis and follow-up care for autistic children. Several countries indicated that national quality assurance standards for diagnosis and treatment were lacking. The

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Country Agents highlighted the importance of dedicated regional and local leaders to set the standards. As a consequence of absent protocols and procedures, regional differences in practices and performance level tended to arise, resulting in a widely varying quality of care delivery, which was noted with concern by Country Agents:

*“Municipalities are autonomous and there may be large differences in the quantity and quality of practices by municipality.” (Finland)*

In addition, care for autistic children is located at the intersection of multiple ministries, such as public health, social care and education, which poses a challenge for making cross-cutting policies of treatment and care.

*“There is a lack of policies and procedures covering children with complex needs especially where an overlap exists between services. In the absence of policies and procedures, institutions start defining on their own what they prioritize, sometimes without consulting stakeholders (e.g. parents and other professionals)”. (Iceland)*

Several of the countries commented that the responsibility for care was delegated to municipalities, which presented a problem due to a lack of specialist knowledge in that arena, and in particular, including autistic children in the ordinary educational system was seen as dissatisfactory.

Several of the country agents noted an improvement for children diagnosed with ASD in that their rights and care needs are more acknowledged. Nevertheless, they also noted a general lack of interest in children with ASD at a ministerial level and a lack of political will to prioritise ASD services with regards to resource allocation. As stated by one Country Agent, priority seemed to be given to other “more important and more urgent” issues to be tackled by the healthcare system (e.g. financing, efficiency and information systems).

Among some countries, there was a focus on ensuring evidence for the policies and standards. And in particular, evidence-based initiatives and an international focus were highlighted as important, regardless of political will. Initiatives regarding care, but also knowledge on prevalence should be taken into account when integrating care. For instance, as stated by one Country Agent, the prevalence of children diagnosed with ASD in their country was 0.016%, compared to a European average of about 2%. The cross-national focus was also emphasized positively in one case, where one country had helped finance another country’s further development of mental health care and rehabilitation services for children and adolescents. The data and evidence available should provide an overview of the care needs, so that policies and standards support coordination.

#### **3.4.4. Resources**

There was a unanimous focus on resources used to perform integrating services for autistic children. Every country in this survey noted resources as a key factor when providing integration and service delivery and specifically, funding and specialist personnel were highlighted as critical. Therefore, the focus aimed at the organisational delivery of integrated treatment and care and not as much the political priority. As stated by a Country Agent:

*“Services are resource limited (personnel and facilities) which impedes the ability of teams to deliver care”. (Ireland)*

Resources were not only stated as “lacking” but were noted as being crucial for performance. One Country Agent states that “*multi-professional teams are available in primary and secondary health care, and the members of teams can participate same further education*”, suggesting that when the resources are available, the integration of services may begin to develop.

Special knowledge about care needs was stated to be found in parental involvement, and several responses indicated that this involvement had, in fact, enhanced the level of specialist knowledge and was perceived as a resource. For illustration, a number of Country Agents pointed to the integration of parents’ associations in decision-making processes as one of the three main opportunities for the integration of services for autistic children. In sum, there is no adequate performance of integration of services without resources.

### **3.4.5. Professional coordination**

All responding countries argued that coordination among relevant professionals is undeniably a key area. Constituents of complex care are provided by many different professionals in the primary, secondary and sometimes the tertiary system, so the organisational structure for collaboration and coordination is critical. Some countries have established care pathways while in other countries, multifaceted care revolves around multi-disciplinary teams. Either way, they must face barriers such as varying levels of engagement from clinicians, different standards of knowledge and expertise, and deficiencies in cross-sectoral and multi-disciplinary oversight. A few countries have suggested that this challenge could be overcome by “ASD centres” and endorsed the establishment of specialised units where the level of knowledge, expertise and service would be available in a single location. For example, one reported that integration between diagnostics and therapy or intervention was linked in the Autism Competence Centre. The challenges are that these highly specialised units of expertise are few.

Despite the challenges, many countries stated that they are moving towards greater organisational integration. One country agent explained that there have been different local, regional and national initiatives directed towards integration of and cooperation between agencies in general, as well as for children with ASD, financed by public funds. These national efforts have aimed to improve the integration of services and the cooperation between child and adolescent psychiatry on the one hand and the municipalities on the other. The implementation of increased cooperation between different service sectors in general and between particular institutions is proposed partly through legislation and regulations at a national level, although bi- or multilateral contracts between institutions is argued to be beneficial.

A number of country agents reported that there was a need for greater awareness of ASD not only at the political level, but also within groups of professionals, as many of the Country Agents reported an absence of multidisciplinary coordinated teams for the care of children with ASD. In addition, an overall lack of staff with specific education and expertise in diagnosing and providing care for autistic children was noted with concern. Several countries stated that screening for ASD was assured through standard development checks and the recognition of ASD in general was improved, but the diagnosis and the following treatment and care was perceived as uncoordinated and thus, in order to provide a continuum of care, the professionals needed to link services based on their common knowledge. As reported, a regional coordinator would be beneficial for both professionals and the child and their family. Additionally, most countries stated the need for collaboration agreements among NGOs and between NGOs and other health care and social care providers.

### 3.4.6. Awareness and advocacy

The majority of the responses suggested that overall there was an increased awareness of ASD and the associated care needs, even though only slow progress is being made. Over a third of countries reported that lobbying and awareness campaigns are being conducted and contributing to public and professional understanding of ASD. However, the special care needs of a child with ASD still need to be highlighted, as the present state of service provision regarding gaps, barriers and facilitators is multi-layered. One Country Agent captured this by stating that one of the main barriers is an “illusion of normal integration” for children with ASD.

Increased public awareness was argued to lead to increased recognition of the difficulties and disabilities the autistic children and their families are experiencing, which provides leverage for increasing political priority. The important public awareness and debate could be fed by the media. One example provided by a Country Agent is a national TV show that focused on the daily reality of living with ASD. Portraying these everyday-life experiences is an important tool in increasing the willingness of decision-makers to discuss and act on this issue.

Political awareness is reported as one of the most influential facilitators or obstacles for improving the integration of care for autistic children. More countries reported that reforms aimed towards “inclusion” in the educational system would not only burden many autistic children and their families, but would also camouflage the special care needs associated with ASD, which could set back the development and awareness. As stated by one country that had experienced reforms of their educational system:

*“Teachers have less time to meet with the pedagogical-psychological counsellors and have less time to care for children with special needs. Also, the reform has led to fewer services offered to children with special needs such as children with autism”. (Denmark)*

NGOs, parents’ associations and other advocacy groups have been reported to have a central role in increasing awareness about ASD care needs. In half of the responses, NGOs and parents’ associations were seen as one of the three main opportunities in integrating care services. The development of uniting and organising these groups is expressed as a continuation of the “intense work” done to put ASD on the public agenda.

### 3.4.7. Integration and service delivery

Integration and service delivery are influenced by policies and standards, resources in place, political and public awareness and coordination of the different professionals, and these four themes are mutually interrelated. For instance, despite the increased public and political awareness influenced by different advocacy groups, an ongoing debate is needed to maintain the developments within the professional sphere. Professional coordination is therefore seen as the link in the integration of services.

A consensus challenge in bridging the gaps suggests that transitions (between health care and social care, between ministries, and between child and adult services) are critical points at which a lack of responsibility for care is a major barrier. Locating accountability and responsibility for care at these frontiers poses a challenge when explicitly formulated policies are lacking. A system that both takes care needs and accessibility into account and ensures political and public interest in policies and standards should be aimed for.

### 3.4.8. Summary

- Overall awareness about ASD, both politically and among the public, has increased.
- Awareness and knowledge about ASD still needs to be increased in order to improve integration and service delivery.
- There is a profound need of professional coordination within and between sectors.
- The most significant barriers relate to a scarcity of funding for resources and specialised personnel.
- ASD advocacy groups have a high degree of influence on both political and public awareness.
- National policies and standards have a significant influence on the performance of service delivery.
- The lack of national policies and alignment between ministries is a barrier to the integration of primary and secondary services.
- There is a high degree of variation at the regional level.

### **3.5. Synthesis of findings on the integration of care for children with ASD**

The above findings were examined collectively and combined into a single model of factors contributing to integrated care for children with ASD. The key themes emerging were prevalent attitudes in the socio-cultural context, access to and organisation of specialists, the important role played by parents, and the organisation of care coordination (see Figure 3.51). These factors were reported to influence integrated care provision for children with ASD, although the existence of services and integration for children with ASD was very variable across the 26 countries that responded.

#### **3.5.1. Awareness and attitudes**

Awareness about ASD among the public and in the political sphere were both found to be relevant factors for the delivery of integrated care for children with ASD. Country Agents reported improved awareness, at least in part due to lobbying and awareness campaigns conducted by Parents' Associations and NGOs and to issues around ASD appearing in the media. Political will and reforms of the education system were also cited as influential in terms of schools for children with ASD, in particular.

Analysis suggested that increased recognition of the care needs of children with ASD was linked with improved policies and standards and brought about by advocacy and awareness campaigns. This in turn may create public and political pressure to develop more comprehensive policies and guidelines, which featured in some countries more than others. National-level quality standards and policies were described as important to avoid large regional variation and inconsistencies in the quality of care. The complex care needs of children with ASD demand input from multiple ministries and the areas of overlap require legal oversight to specify accountability and procedure. The policy framework plays a large part in the process of accessing specialist care and in the organisation of professional expertise and specialisation.

#### **3.5.2. Specialisation**

The existence of specialist knowledge within the healthcare and social care systems is crucial to ensuring that children with ASD receive safe and efficient care. However, reports of shortages of appropriate specialists, leading to substandard care and long waiting lists, were common. Funding was reported as a key issue, as it was directly linked with a scarcity of appropriate specialists and the political will to provide resources. Specialist knowledge follows from a combination of political, parental and professional awareness about ASD, with Parents' Associations and NGOs supplying information and experience of the daily needs of autistic children and professionals providing a clinical understanding of the needs and gaps in service delivery. These inform the political system, which should facilitate policies and allocate resources. Access to specialists was also influenced by geographical location, in that there were large regional differences in approach and availability and a concentration of professionals in ASD centres and cities, sometimes to the detriment of services in rural areas.

Findings suggest that a higher degree of specialisation in the national healthcare and social care systems facilitates formal care pathways, leading to easier access to specialist care. Countries with a spectrum of specialized units involved in a stepped care approach reported being satisfied with the national care service, suggesting that the role of gatekeepers in referring the children to specialists may be a key factor regardless of where the specialists are placed. The organisation of specialists

influences the general level of care offered to the whole ASD population. The degree of specialisation determines the number of specialists and the organisation determines the pathway of the specialists.

The process of accessing this specialist knowledge was emphasised as a central factor for receiving integrated care. Specialists may be accessed as part of multidisciplinary teams, in an *Autism Competence Centre*, or via referrals from primary care. Comprehensive care guidelines specifying the type of professional required and within which organisation were described as beneficial, and single location or single team service delivery were also seen to aid access.

### 3.5.3. Formalised care coordination

Coordination between the numerous specialists and community-based services needed by the child tends to be performed by a combination of the parents and professionals, and parents, as the main care providers, as central to the child's care. Parents fulfil a variety of roles, which often includes that of care coordinator, and therefore, the availability and access to specialists and the structure of expertise within an organisation affects the balance of responsibility between parent and professional. The more comprehensive the coordination within the healthcare and social care systems, the lighter the organisational burden on parents.

The importance of professional coordination was emphasised by all responding countries, as complex care for ASD requires input from primary, secondary and sometimes tertiary healthcare as well as multiple agencies with responsibility for the social care, education and socioeconomic supports required by the child and their family. Coordination may be described in policies or legislation, incorporated into care pathways or enacted within multidisciplinary teams, sometimes in a single location. However, in practice and particularly when legal structures are not available, the standard to which care coordination is performed is affected by the availability, engagement and inclination of the relevant professionals.

Communication between agencies is an important aspect of care coordination that comes to the fore when integration is lacking. Specifically, clarity of and commitment to agreed roles and responsibilities (and who has overall responsibility for the child in particular) is key when multiple actors from multiple sectors are involved in the child's care. Personalised care plans were described as a useful vehicle for recording and acting on these roles and responsibilities and for legally and functionally securing care.

Organisational integration of services across and within sectors was described by some countries as a facilitator of seamless, safe and efficient care for children with ASD, and integrated care are best placed to respond to their varying care needs over the course of their development. Although recognised as key, many countries reported fragmentation between agencies resulting in gaps in care provision and recommended more comprehensive integration. Participants described a variety of local, regional and national initiatives intended to solve this problem, including pilots of single-location specialist centres, types of multi-disciplinary teams, regional professional networks, and national standards and legislation. Findings recommend that solutions based on horizontal (between health and social services, such as multi-disciplinary teams) and vertical (across primary, community, hospital and tertiary care services) integration.

Requirements and models for supporting children with complex mental health needs and the primary care interface

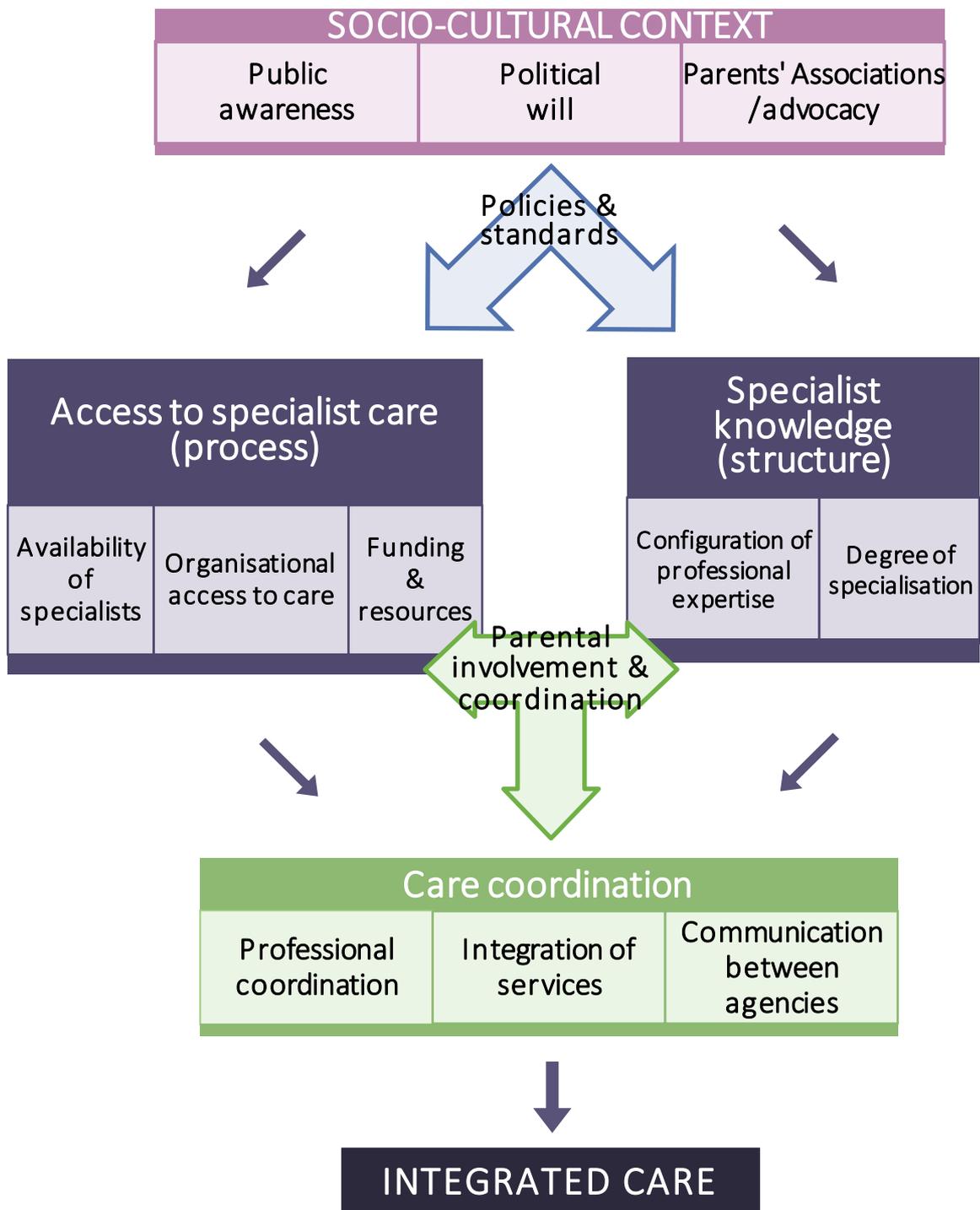


Figure 3.51: Synthesis of findings on the integration of care for children with ASD

## 4. Findings: The Interface of Care for Children with ADHD

This chapter reports the findings regarding the integration of care for adolescents with Attention Deficit Hyperactivity Disorder (ADHD) across MOCHA study countries. Responses from 25 of 30 (83.3%) of the MOCHA study countries were returned (*Appendix 2*). The first part of this chapter describes the findings from the categorical questions from the *Standards for Systems of Care for CYSCHN*, followed by business models representing key aspects of care for children with ADHD. The third and fourth parts of this chapter present the thematic networks that emerged from the qualitative commentary from *Lucile-Packard Standards* and the *Survey of Change*, using the method described by Attride-Stirling [30]. Finally, a synthesis of the above findings is presented.

### 4.1. Structures and processes of care in place for a child with ADHD

Results are presented by sub-section of the adapted *Standards for Systems of Care for CYSCHN*.

#### 4.1.1. Screening, assessment and referral

Respondents were asked about screening, assessment, referral and follow-up for children with and without potential indications of ADHD.

##### 4.1.1.1. Policies and procedures for ongoing preventative care, screening and developmental checks

Of the 25 countries, nine reported having both policies and procedures in place to assure that a child with ADHD receives ongoing preventative care screening and developmental checks with regards to their ADHD diagnosis. Three countries reported having only a policy, five reported only a procedure and seven reported having neither. One country did not respond regarding procedures. The responses are displayed in Figure 4.1 below.

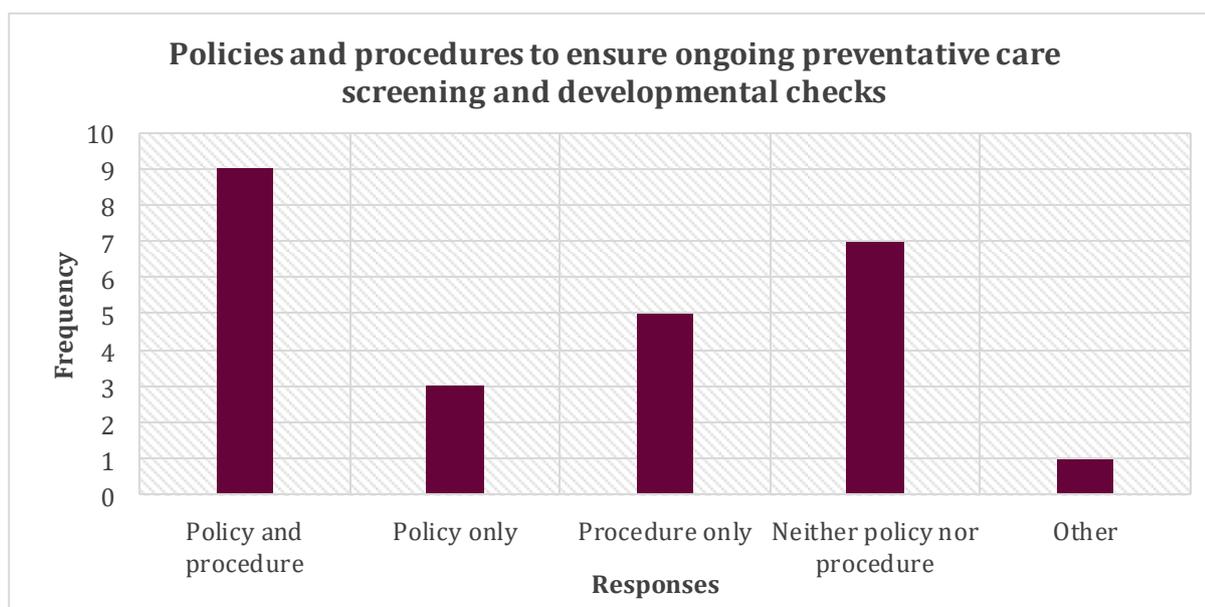
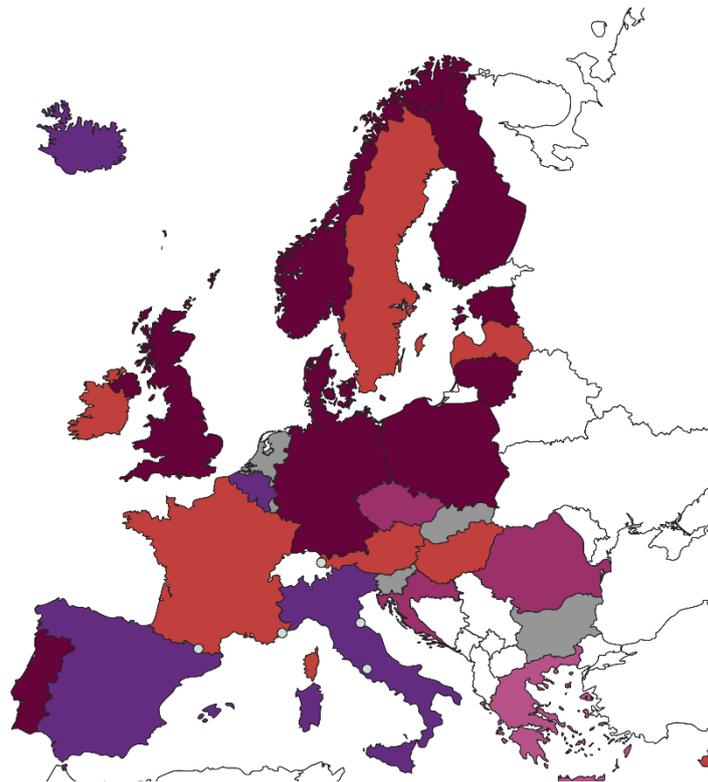


Figure 4.1: Policies and procedures to ensure ongoing preventative care screening and developmental checks

### Policies and procedures to ensure ongoing preventative care, screening and developmental checks



Map 4.1: Policies and procedures to ensure ongoing preventative care, screening and developmental checks

#### 4.1.1.2. Policies and procedures to document and communicate screening results

The questionnaire included items on policies and procedures to document and communicate screening results to a) all care services involved in the care of the child and b) to the child's parents or guardians.

Around half of responding countries (n=13) did not have policies and procedures in place to document and communicate the results of such screening to all care services involved in the care of the child, for example, general practitioners or primary care paediatricians, community nurses, school health services and secondary care. Seven countries had both policies and procedures for this purpose. A minority had either policies (n=1) or procedures (n=3) (see Figure 4.2).

Similarly, seven countries had both policies and procedures to document and communicate screening results to parents or guardians. Nine had neither policies nor procedures, three had policies only and four had procedures only.

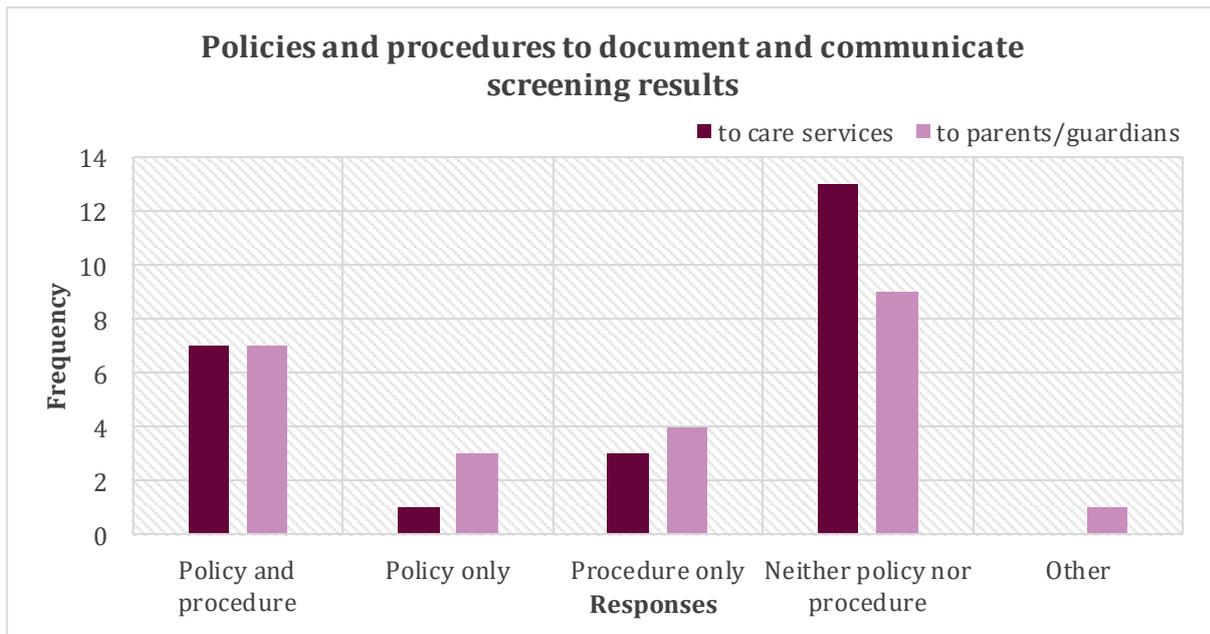


Figure 4.2: Policies and procedures to document and communicate the results of such screening to all care services and to parents or guardians

#### 4.1.1.3. Policies and procedures to assess family competencies that may influence providing care

The majority of countries (n=17) reported that there were no policies and procedures in place to assess family competencies, for example knowledge and ability, that may influence their capacity to provide care for a child with ADHD. Seven countries reported that such policies or procedures were in place and one country did not respond.

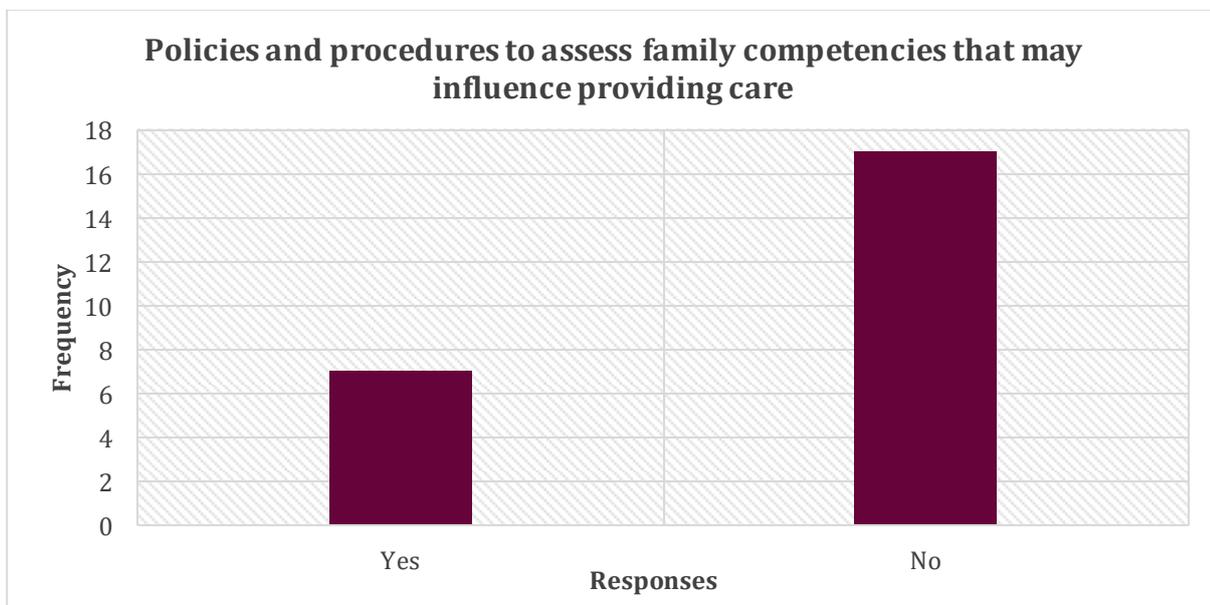
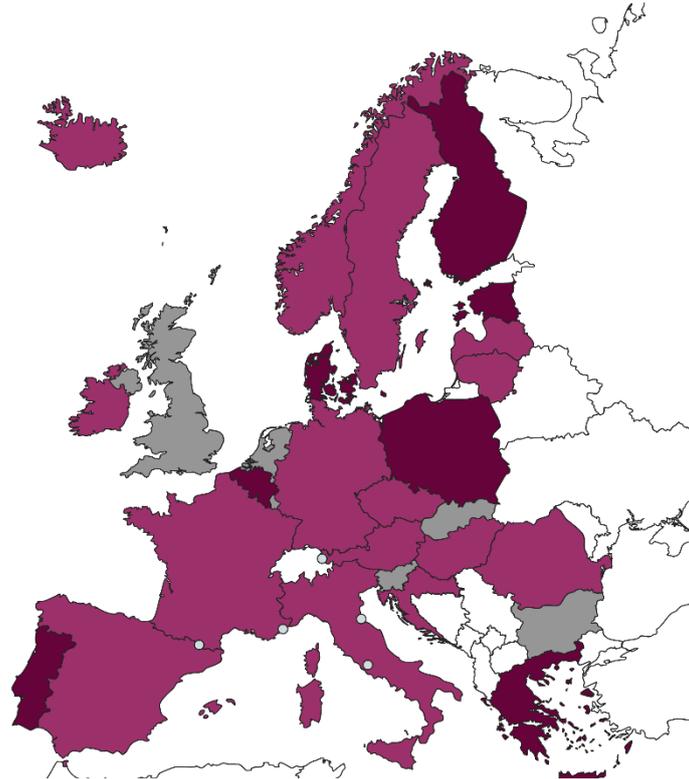


Figure 4.3: Policies or procedures to assess family competencies that may influence providing care

**Policies and procedures to assess family competencies that may influence providing care**

- Yes
- No
- No response
- Non-Mocha country



Map 4.2: Policies and procedures to assess family competencies that may influence providing care

**4.1.2. Access to Care**

**4.1.2.1. Systems to identify all healthcare and social care providers who care for children with ADHD**

Half of the included countries (13 of 25) had systems in place to identify all healthcare providers caring for children with ADHD. Fewer countries (n=5) reported that there was a system to identify all social care providers caring for children with ADHD, with 19 reporting that they had no such system. One country did not provide an answer regarding social care providers.

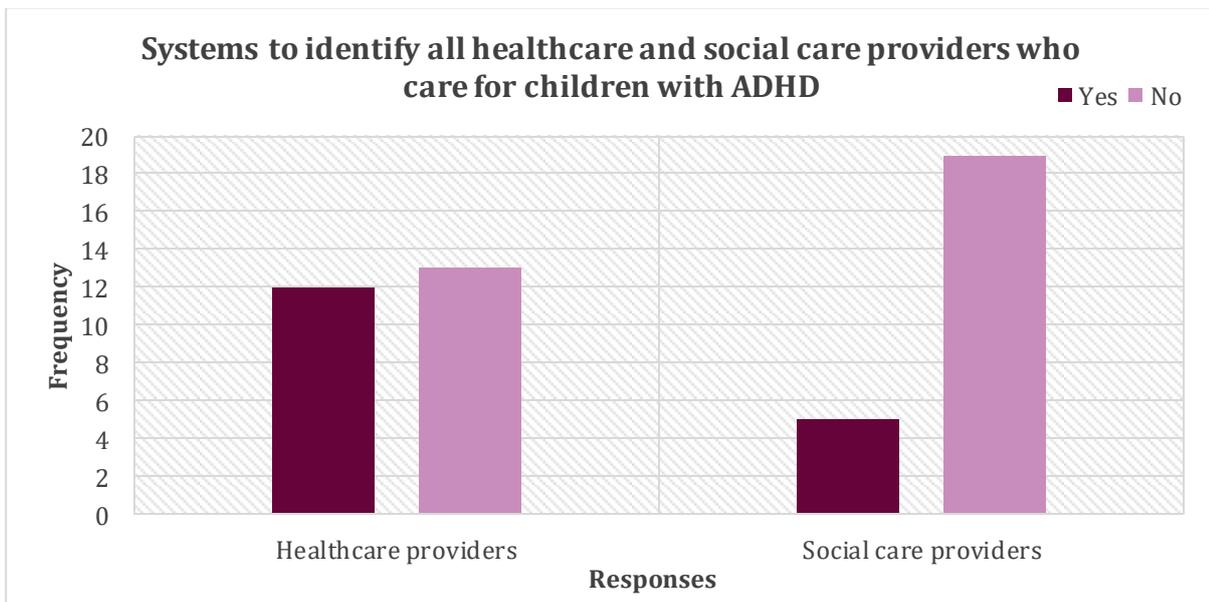


Figure 4.4: Systems to identify all healthcare and social care providers who care for children with ADHD

#### 4.1.2.2. Multi-disciplinary guideline of care for children with ADHD

Fewer than half of the countries that responded reported having a multi-disciplinary guideline of care for children with ADHD (n=10), while 15 reported that there was no multi-disciplinary guideline.

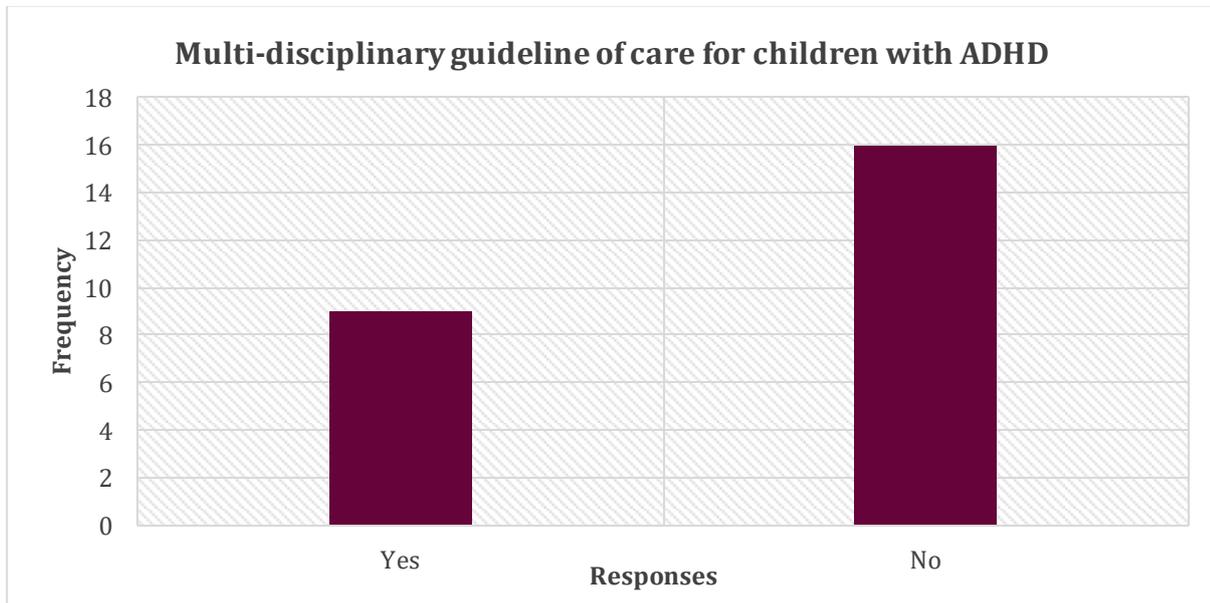
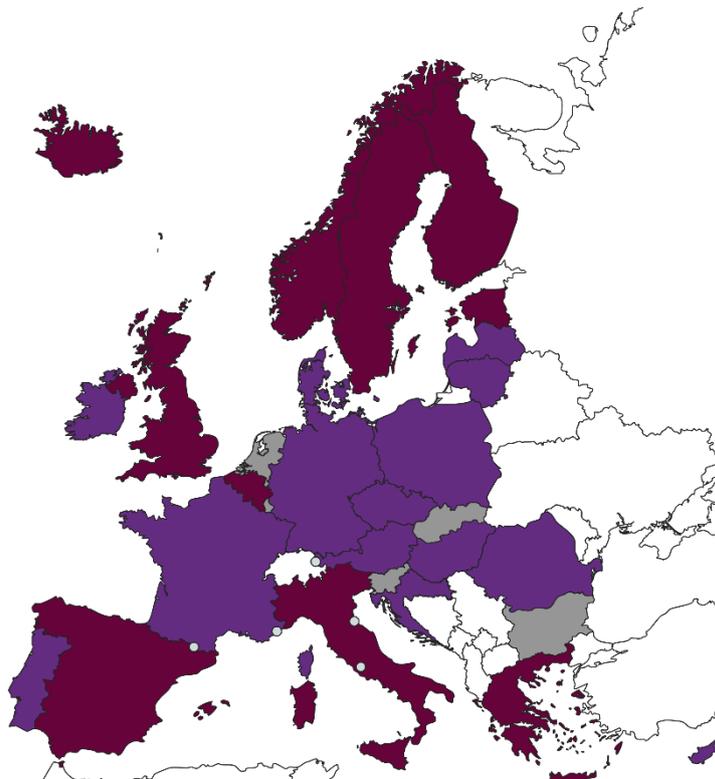


Figure 4.5: Multi-disciplinary guideline of care for children with ADHD

#### Multi-disciplinary guideline of care for children with ADHD

- Yes
- No
- No response
- Non-Mocha country



Map 4.3: Multi-disciplinary guideline of care for children with ADHD

#### 4.1.2.3. Formal training on how to best care for children with ADHD is provided to the parents or guardians

Formal training on how to best care for children with ADHD is provided to the parents or guardians in half of responding countries (n=14). In the remaining ten countries, such training is not provided. One country did not answer.

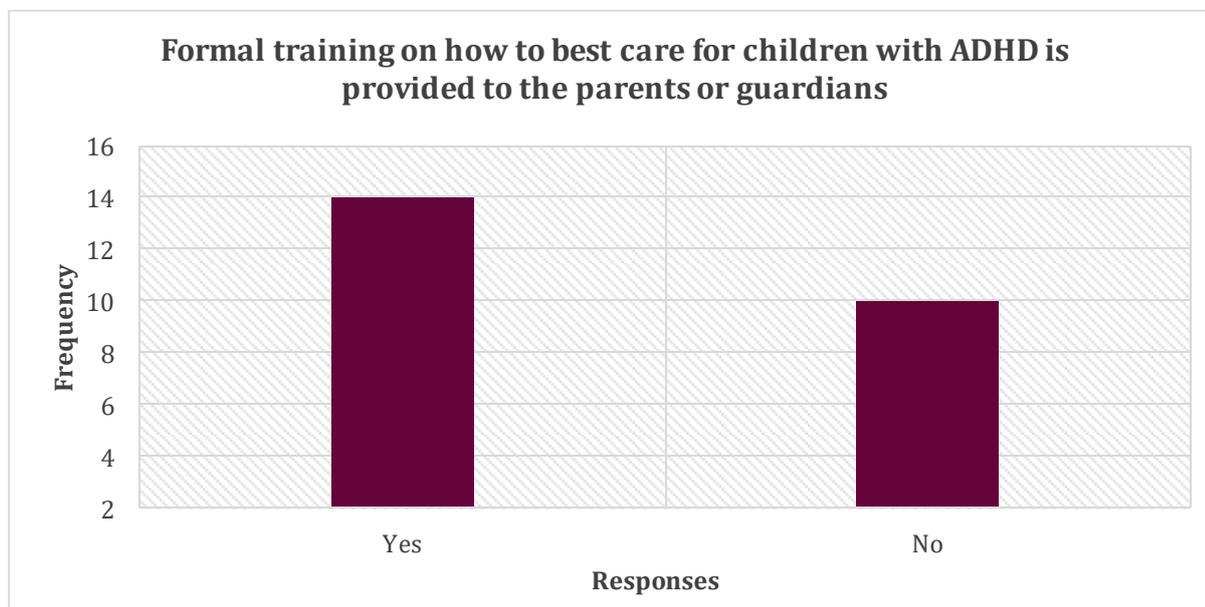


Figure 4.6: Formal training on how to best care for children with ADHD is provided to the parents or guardians

#### 4.1.2.4. Policies or procedures to ensure that parents have the capacity to incorporate care training into their child's daily routine

Of the fourteen countries who reported that formal training for parents is available, three countries (Estonia, Finland and Norway) reported that both policies and procedures were in place to ensure that parents have the capacity to incorporate care training into their child's daily routine. However, in seven countries, formal training is given but there are neither policies nor procedures to assess the parents' capacities to apply the training. In one country, there are procedures only. Three countries did not respond to this item.

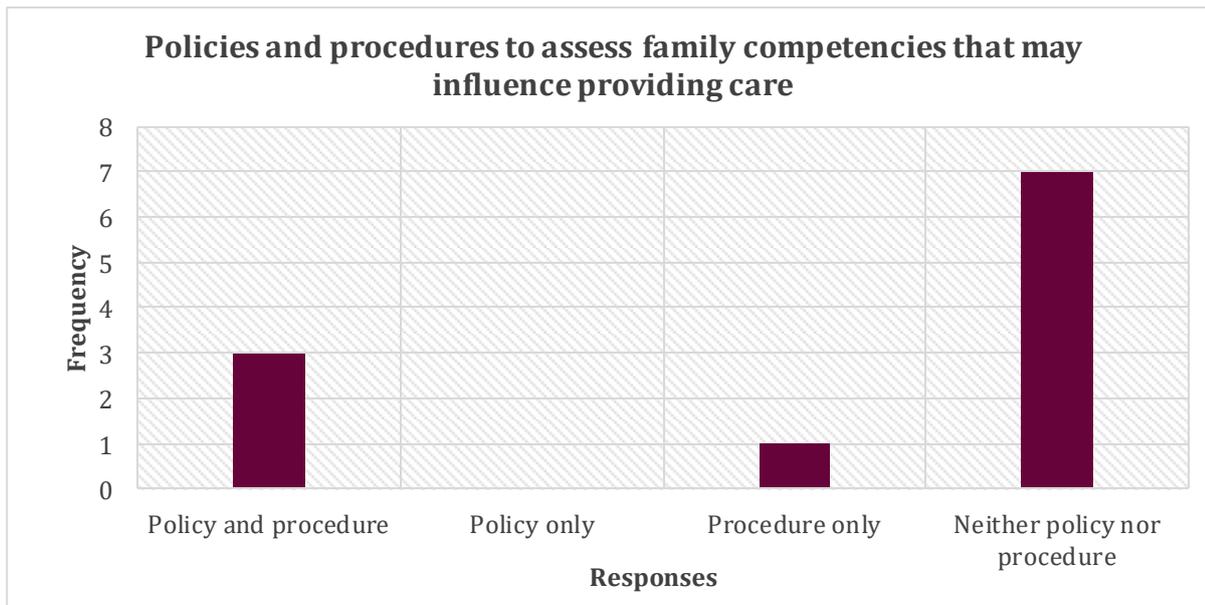


Figure 4.7: Policies or procedures to ensure that parents have the capacity to incorporate care training into their child’s daily routine

**4.1.2.5. Policies or procedures to provide an overview of the interface between the primary, secondary and social care system**

The majority of countries (n=17) did not have a policy or procedure to provide an overview of the interface between the health care and social care system responsible for a child with ADHD’s primary and secondary care. Seven countries reported that they did have such policies and one country did not respond.

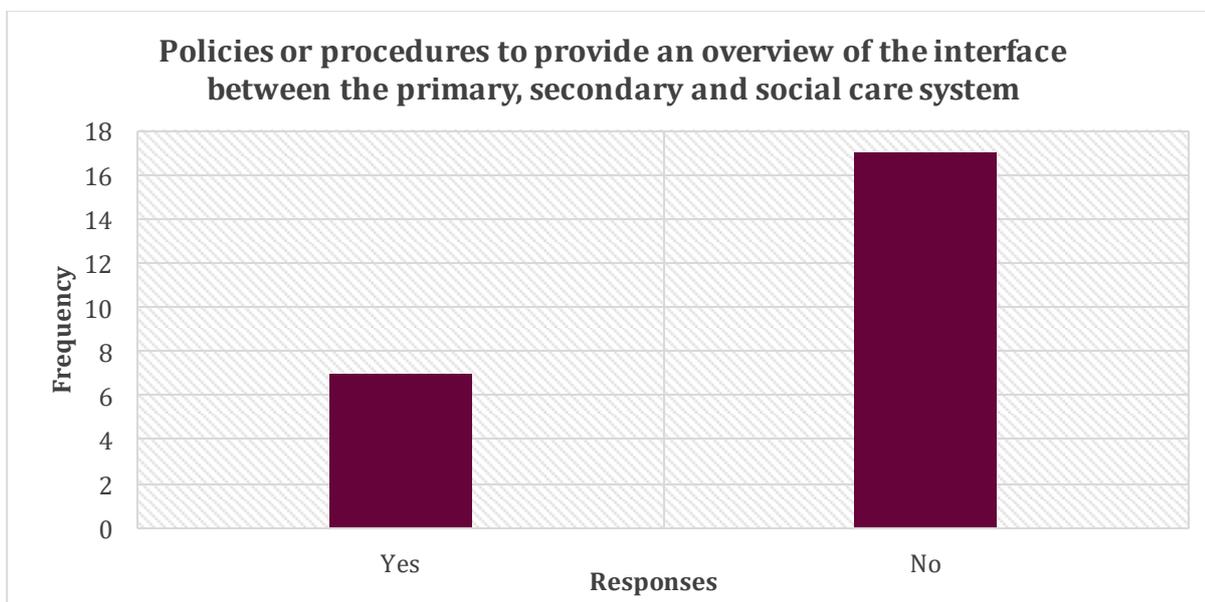


Figure 4.8: Policies or procedures to provide an overview of the interface between the primary, secondary and social care system

#### 4.1.2.6. Policies or procedures to ensure children with ADHD are cared for by the same healthcare and social care providers every time

Nine countries had policies or procedures in place to ensure that children with ADHD are cared for by the same individual or team of healthcare providers every time, and sixteen did not have such healthcare policies or procedures. Even fewer countries had policies or procedures to ensure children with ADHD are cared for by the same social care providers (n=6), while eighteen countries did not have these policies or procedures regarding social care teams.

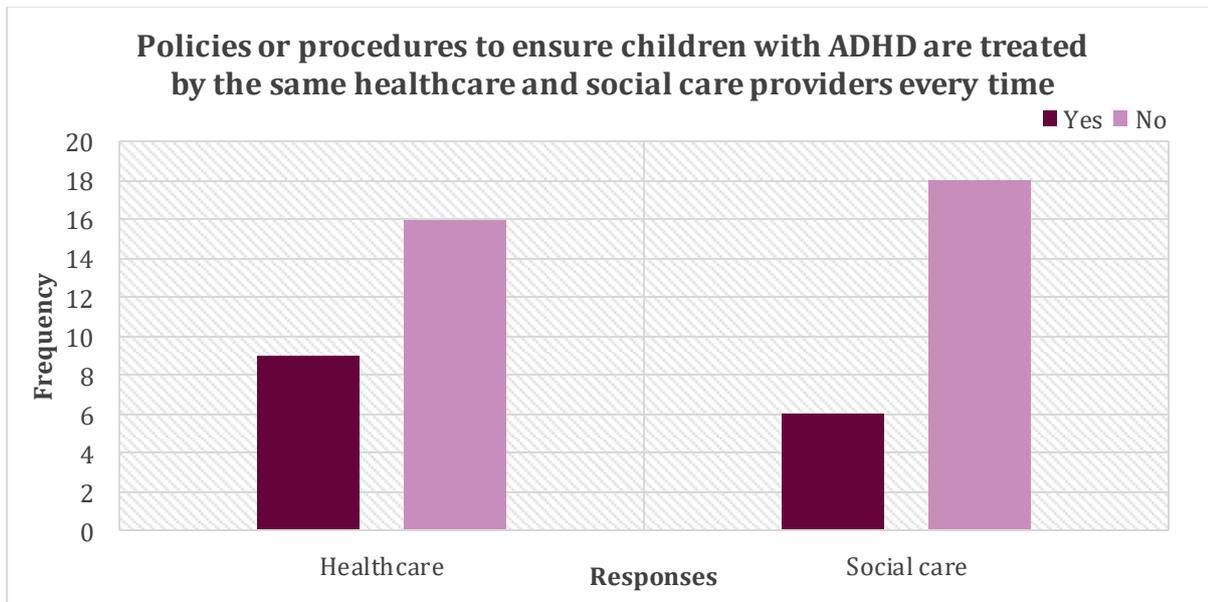


Figure 4.9: Policies or procedures to ensure children with ASD are treated by the same healthcare and social care providers every time

#### 4.1.2.7. A child with ADHD can access primary care regardless of care provided in secondary care and vice versa.

A large majority of countries reported that a child with ADHD can access primary care regardless of care provided in secondary care and vice versa (n=21), with three countries reporting that this was not possible in their countries (Cyprus, Malta and Norway). Ireland reported that it was possible to access primary care regardless of the care provided in secondary care, but that to access secondary care, a referral via a GP must be made.

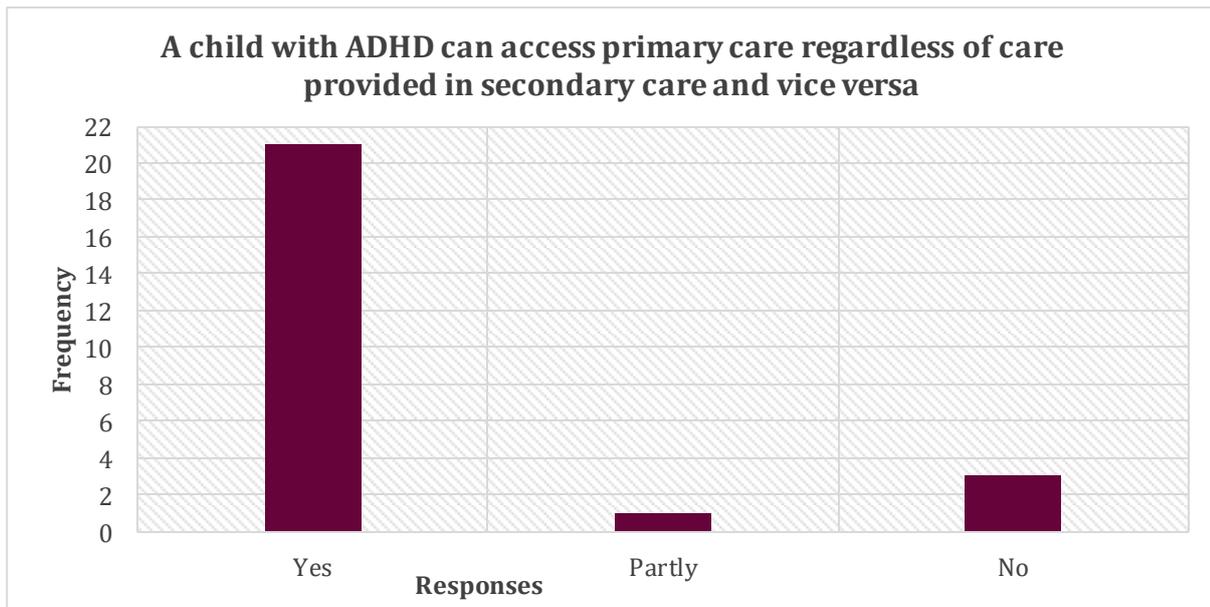


Figure 4.10: A child with ADHD can access primary care regardless of care provided in secondary care and vice versa

#### 4.1.2.8. Provision of transportation to care services for children with ADHD

Respondents selected the types of transport provision that are available in their country. The majority reported that transportation to care services for children with ADHD was provided by parents with support from the state (n=14). Only five countries reported that healthcare providers offered transportation to care services for children with ADHD and ten reported that social care providers did so.

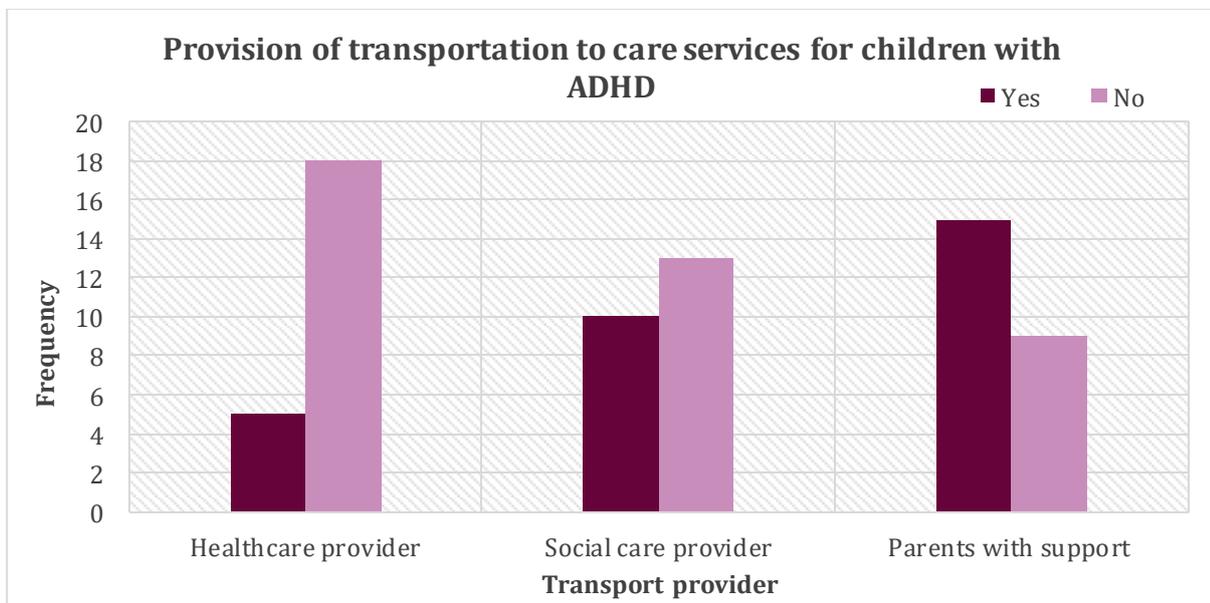


Figure 4.11: Provision of transportation to care services for children with ADHD

#### 4.1.2.9. Policies or procedures to ensure that all information provided to families of children with ADHD is linguistically and culturally appropriate

Respondents were asked whether their countries have policies and procedures to ensure that information given to families of children with ADHD is a) linguistically and b) culturally appropriate.

Most countries did not have either policies or procedures to ensure information is linguistically (n=11) and culturally (n=18) appropriate for families. Seven countries had both policies and procedures regarding linguistic appropriateness but only two reported having both policies and procedures regarding cultural appropriateness. Four countries had policies only to ensure that information is linguistically appropriate and three reported that they had policies regarding cultural appropriateness. Two countries did not respond regarding cultural appropriateness of materials.

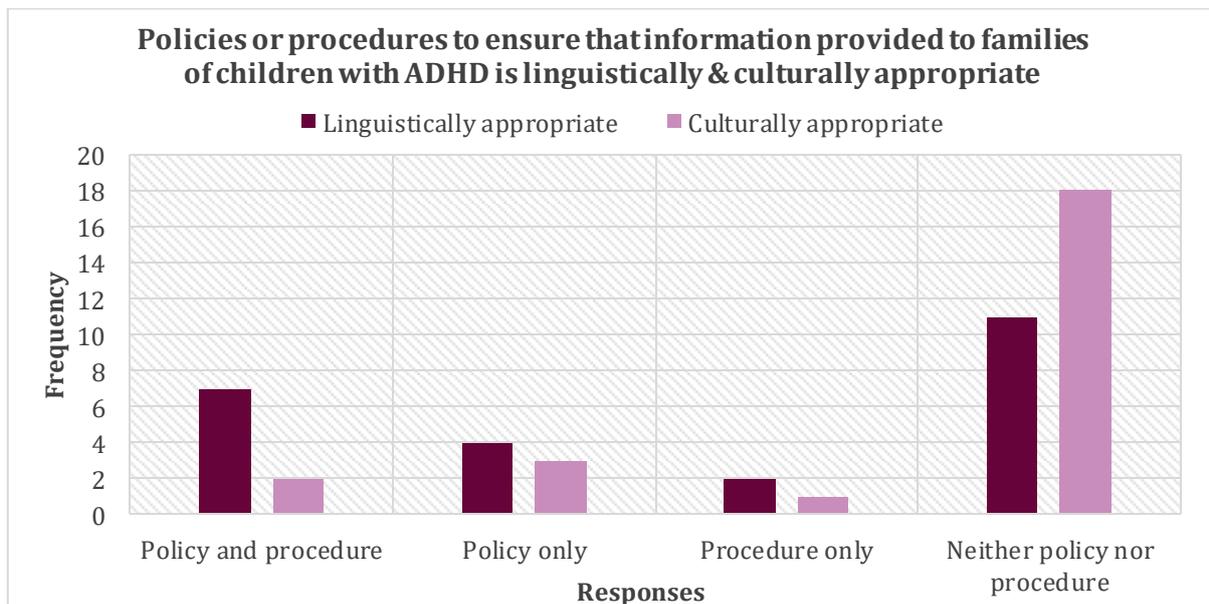


Figure 4.12: Policies or procedures to ensure that all information provided to families of children with ADHD is linguistically appropriate

#### 4.1.3. Care Coordination

##### 4.1.3.1. Policies and procedures promoting access to care coordination for children diagnosed with ADHD

Seven countries reported having both policies and procedures promoting access to care coordination for children with ADHD, and thirteen reported having neither policies and procedures. One country reported having policies only (Estonia) and four did not respond to both items.

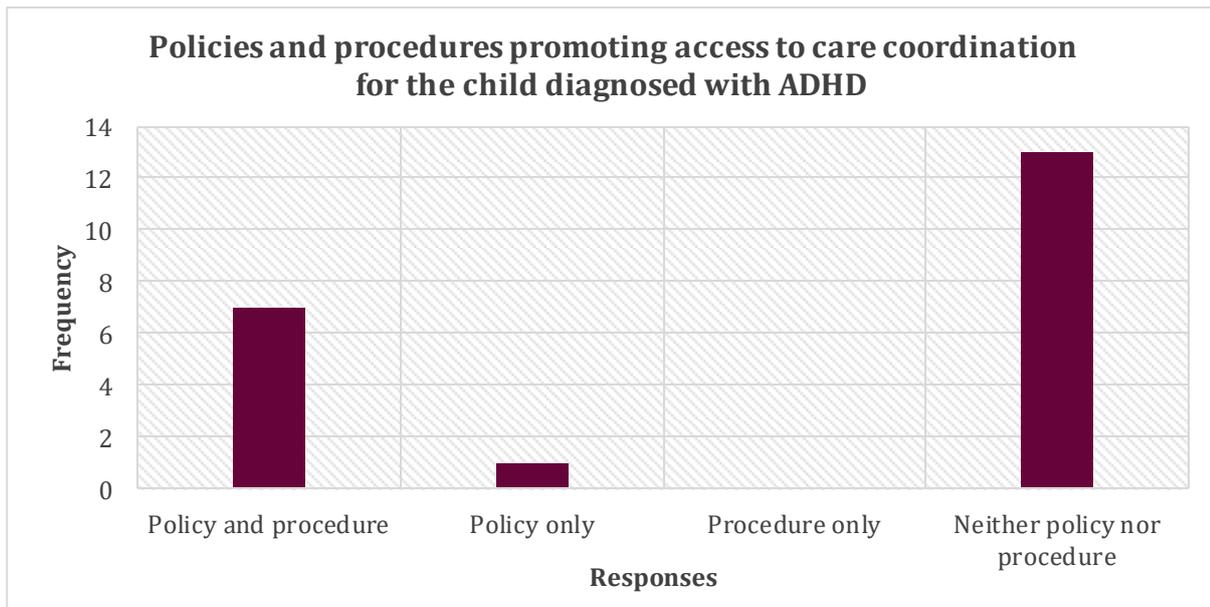


Figure 4.13: Policies and procedures promoting access to care coordination for children diagnosed with ADHD

**4.1.3.2. There is a specific care pathway for children with ADHD**

Three countries reported that there is a full care pathway for children with ADHD, with eleven indicating that the care pathway is only partial. The nature of the partial pathway varies, but may describe certain phases of a pathway, exist in limited areas or institutions, or be recommended rather than mandatory. Eleven countries reported that there is no specific care pathway for children with ADHD.

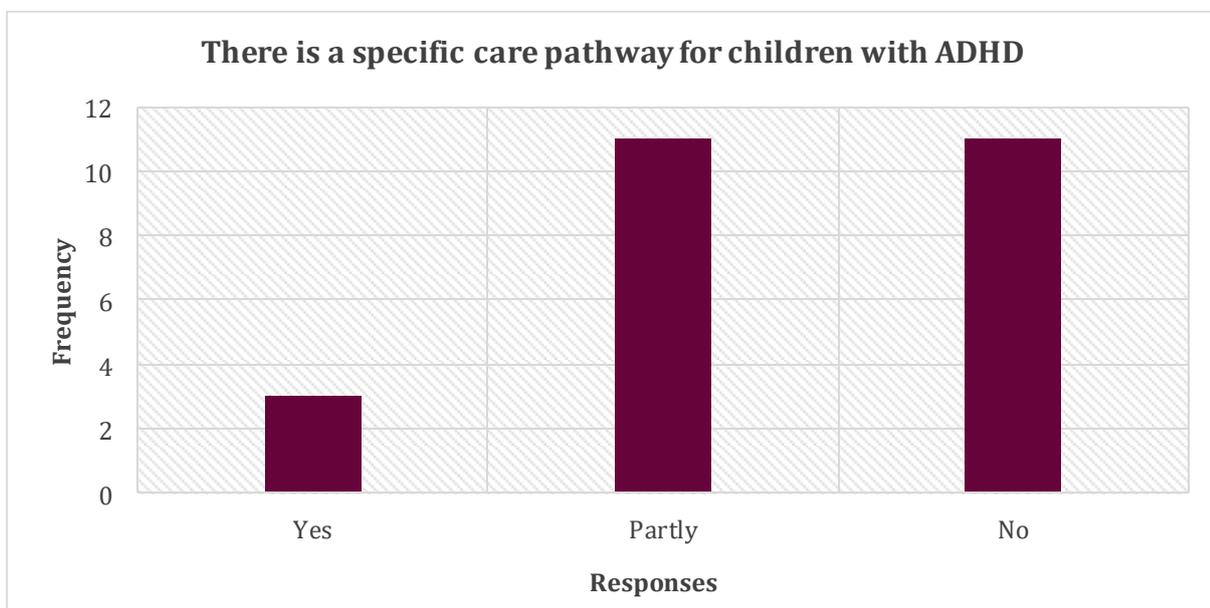
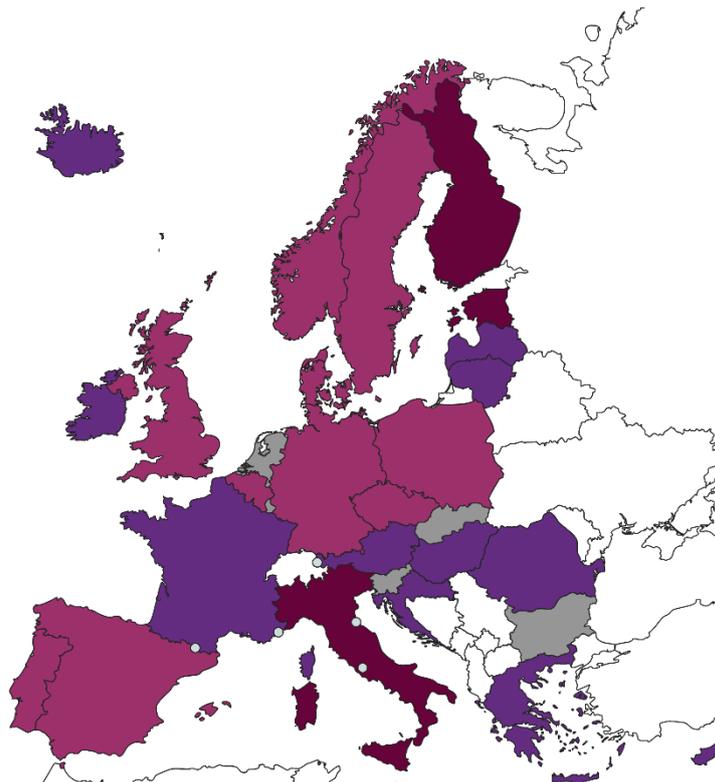


Figure 4.14: There is a specific care pathway for children with ADHD

**There is a specific care pathway for children with ADHD**

- Yes
- Partial pathway
- No
- No response
- Non-Mocha country



Map 4.4: There is a specific care pathway for children with ADHD

**4.1.3.3. Policies or procedures that clearly describe the role of each provider in a care pathway for children with ADHD**

Of the fourteen countries with a full or partial care pathway for children with ADHD, eight had policies or procedures that describe the role of each care provider and five did not, all of which had only a partial care pathway. One country did not respond to this item.

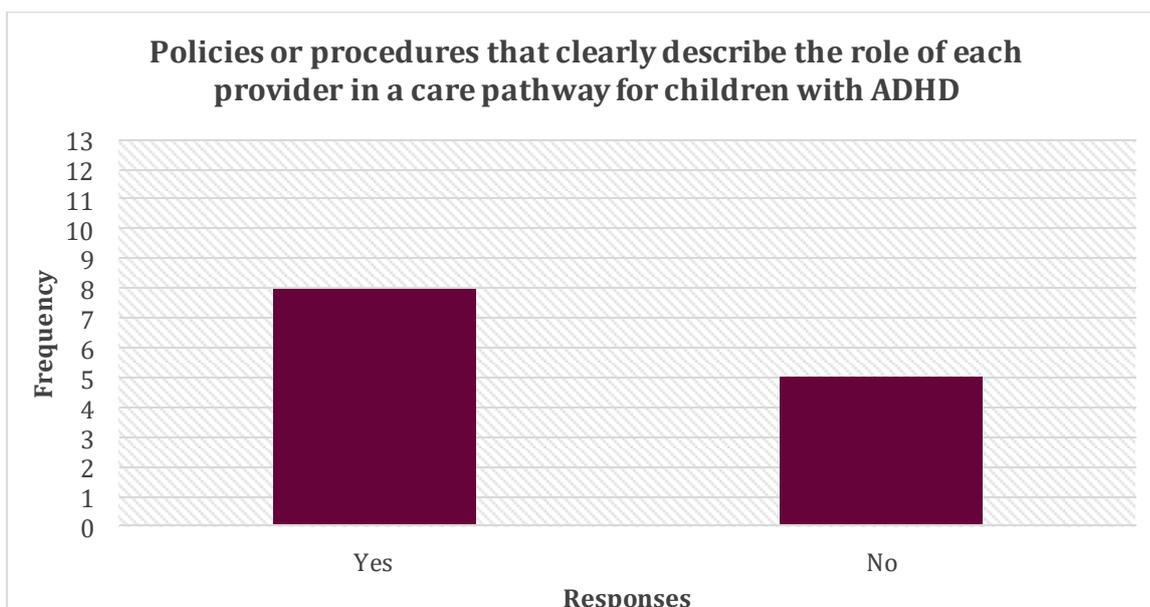


Figure 4.15: Policies or procedures that clearly describe the role of each provider in a care pathway for children with ADHD

#### 4.1.3.4. Policy or procedure to integrate primary and secondary care in the care pathway for children with ADHD

Of the fourteen countries that have a full or partial care pathway, six have policies or procedures to ensure the integration of primary and secondary care for children with ADHD, and eight do not have such procedures. Of the eight countries that reported having a such an integration procedure or policy, five indicated that this facilitates continuity between primary and secondary care in the pathway.

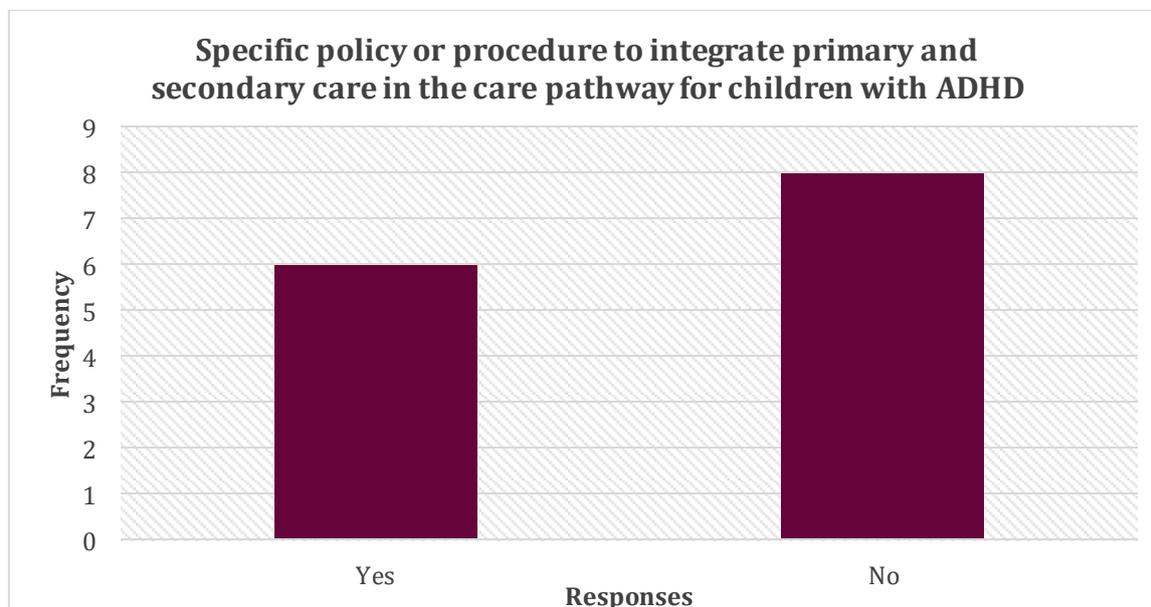


Figure 4.16: Specific policy or procedure to integrate primary and secondary care in the care pathway for children with ADHD

#### 4.1.3.5. Procedures ensuring a personalised written care plan for children diagnosed with ADHD

Twelve countries reported having procedures to ensure a personalised written care plan for children diagnosed with ADHD and twelve countries reported having no such procedures. One country did not respond to this item.

The absence of a specific care pathway for ADHD did not preclude policies or procedures ensuring that a written personalised plan is in place. All three of the countries who reported having a specific care pathway also reported having a procedure regarding personalised plans, but four of ten countries who reported no care pathway and four of eleven who reported a partial pathway also did so.

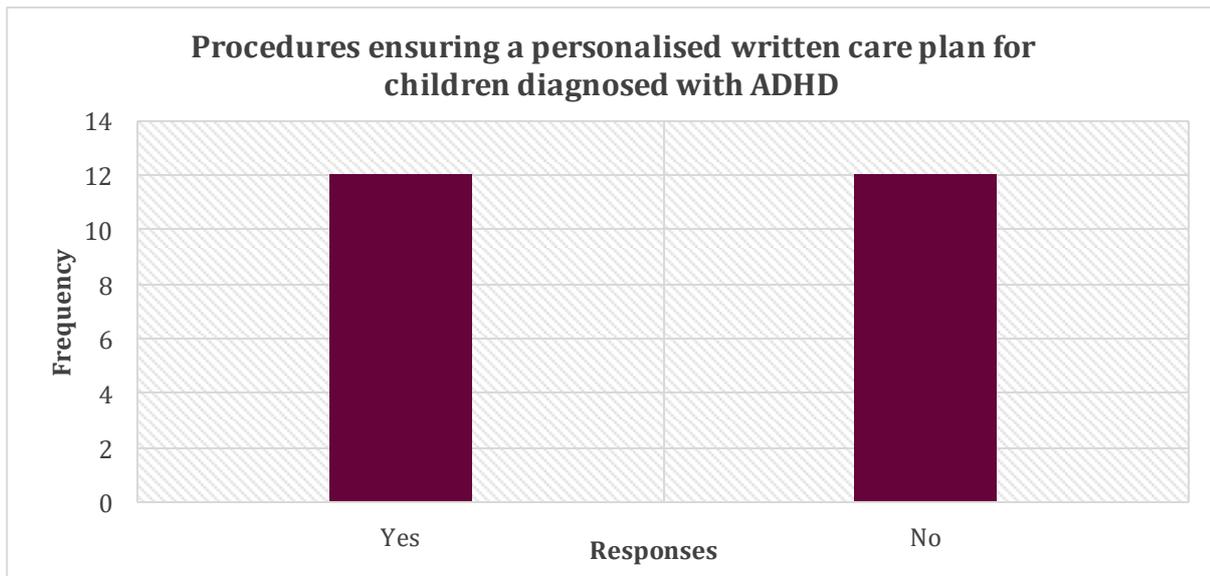
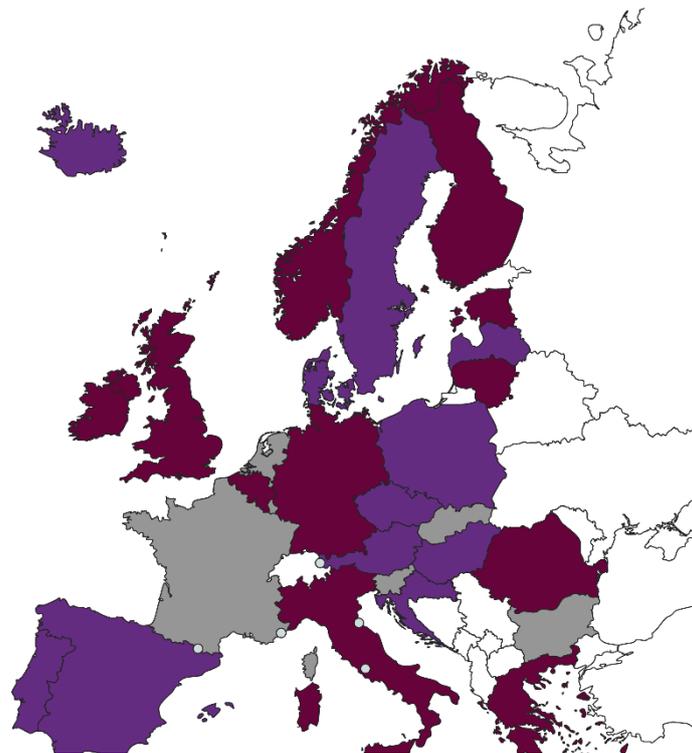


Figure 4.17: Procedures ensuring a personalised written care plan for children diagnosed with ADHD

**Procedures ensuring a personalised written care plan for children diagnosed with ADHD**

- Yes
- No
- No response
- Non-Mocha country



Map 4.5: Procedures ensuring a personalised written care plan for children diagnosed with ADHD

**4.1.3.6. Persons consulted with in the development of the personalised written plan of care for a child with ADHD**

Eleven countries reported having full or partial procedures ensuring a personalised written plan of care, but additional countries responded to questions regarding the persons consulted during the making of the plan and the elements integrated into the plan (see 4.1.3.7 below). This may suggest that written personalised care plans are made even when there are no policies and procedures to enforce this.

A total of 19 countries reported which persons were consulted in the development of a written care plan for children with ADHD. Sixteen of these reported that the parents or guardians and the relevant

healthcare providers are consulted with in the development of the personalised written plan of care. This included four countries that had reported a lack of procedures regarding making a written personalised care plan (Croatia, Denmark, Poland and Portugal). Thirteen respondents indicated that social care providers are consulted in the making of this care plan, including three countries where there are no procedures ensuring the plan is made (Croatia, Denmark and Portugal).

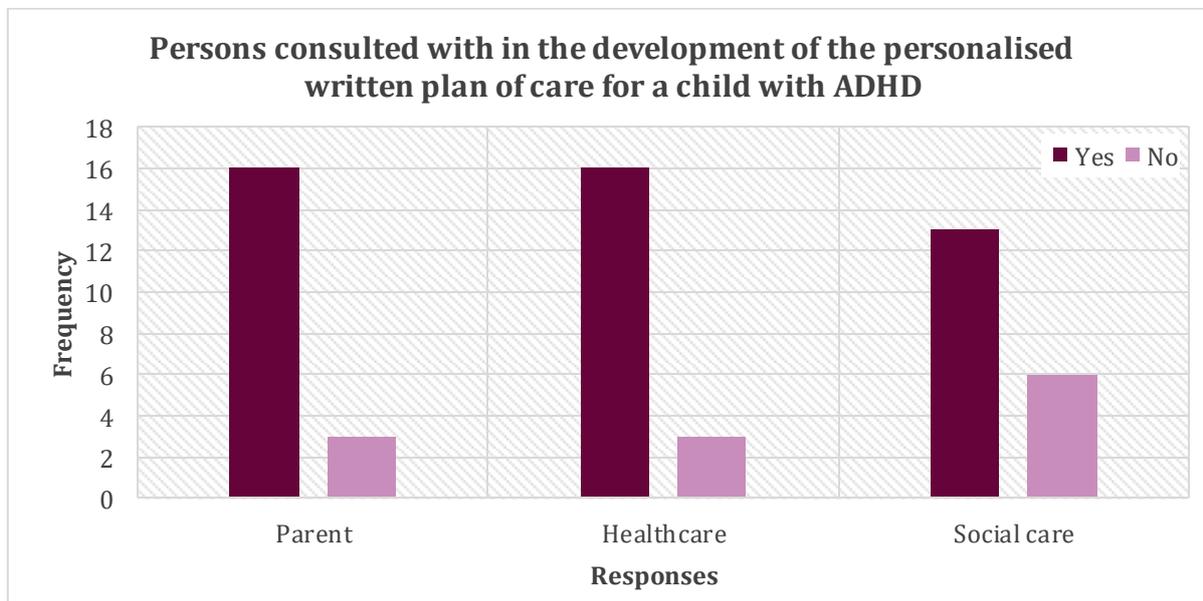


Figure 4.18: Persons consulted with in the development of the personalised written plan of care for a child with ADHD

#### 4.1.3.7. Elements of care integrated in the personalised written care plan for a child with ADHD

Nineteen countries answered this question, after countries with no written personalised care plans (with or without policies and procedures) were removed. Eighteen (all except one) reported that developmental health, mental health and physical health are incorporated into the personalised written plan of care and fifteen countries include social health. Eleven countries included hearing and vision health in the personalised care plan. The least common element of care included in the personalised written care plan was oral health (n=9).

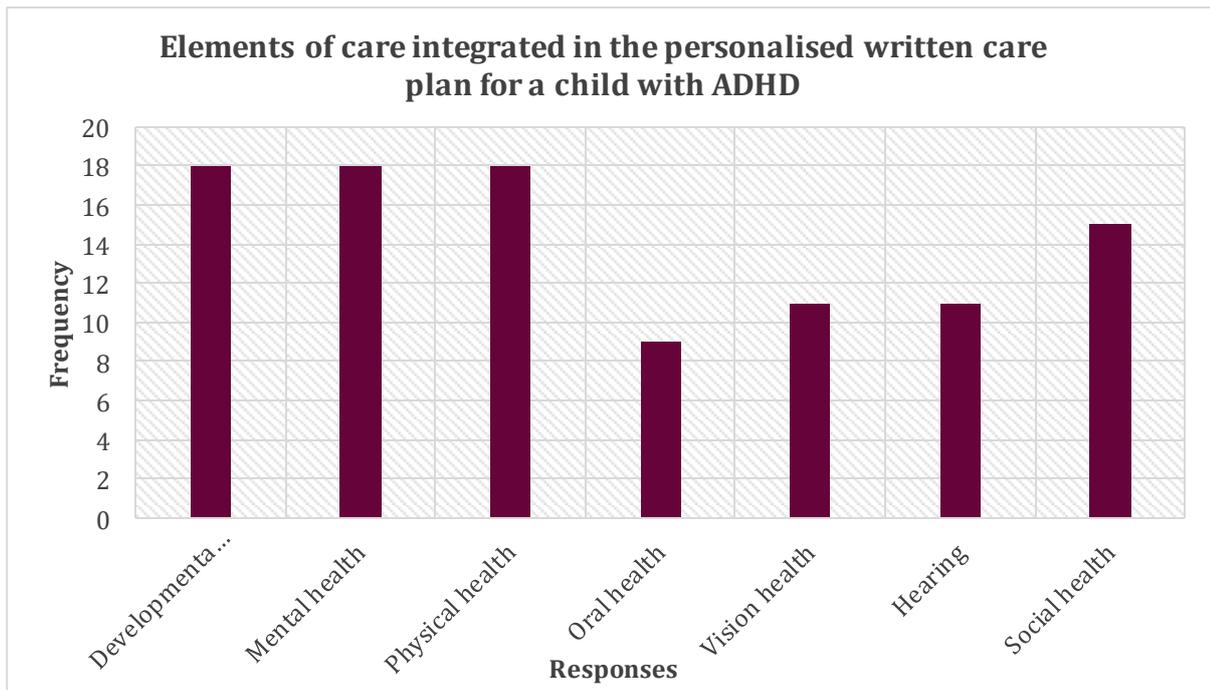


Figure 4.19: Elements of care that are integrated in the personalised written care plan for a child with ADHD

**4.1.3.8. Hospitals that provide mental health care for children with ADHD have a discharge planning coordinator to organise transition to home**

Almost half of responding countries (n=10) reported that hospitals providing mental health care for children with ADHD have a discharge planning coordinator to organise transition to home or other community-based settings, while twelve did not. Three countries did not respond to this item.

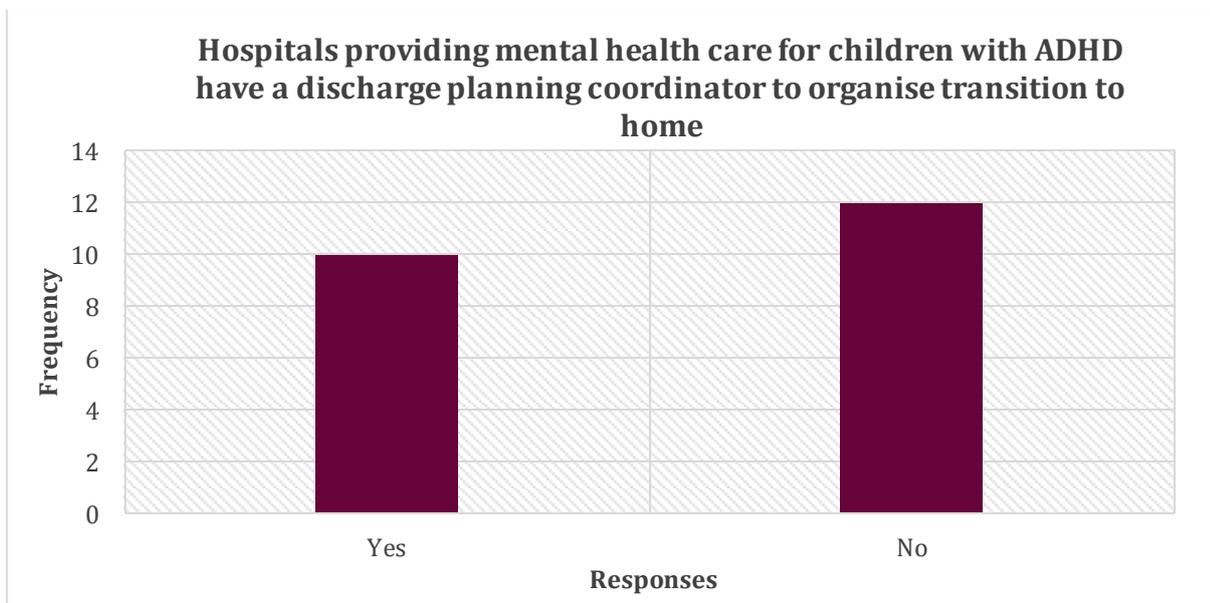


Figure 4.20: Hospitals that provide mental health care for children with ADHD have a discharge planning coordinator to organise transition to home

#### 4.1.4. Community-Based Services and Support

##### 4.1.4.1. Community-based services are a key component of the care approach for children with ADHD

Fifteen countries agreed that community-based services, such as local initiatives or voluntary organisations, are key components of the care approach for children with ADHD in their countries. Nine said they are not key in their countries and one did not respond.

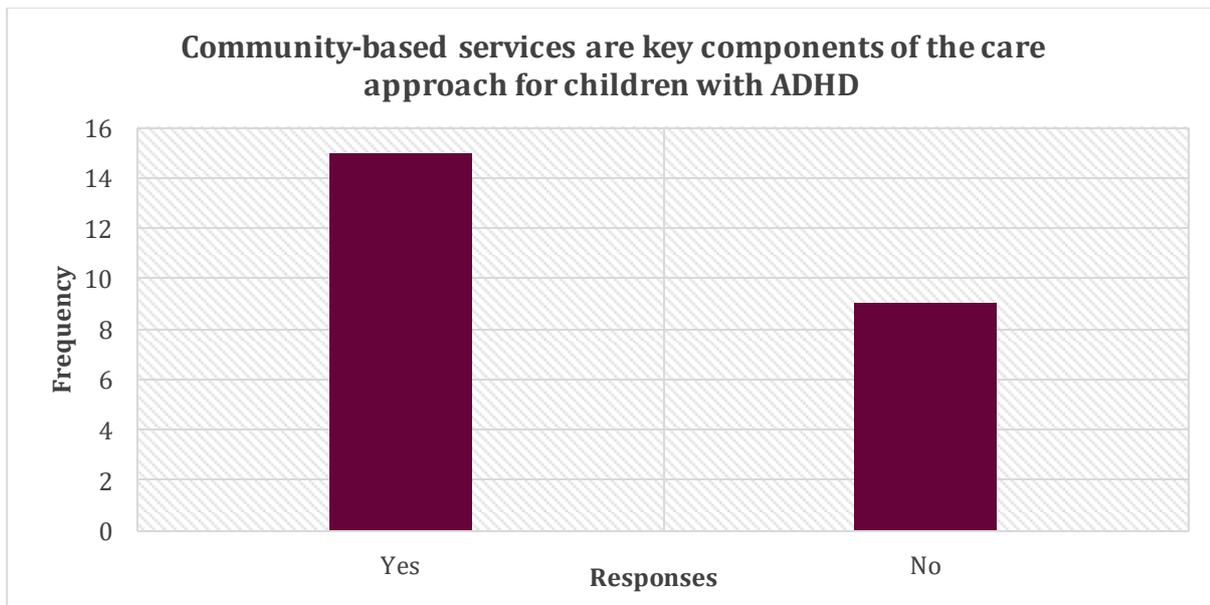


Figure 4.21: Community-based services are key components of the care approach for children with ADHD

##### 4.1.4.2. Family advocacy groups are involved in making recommendations to home and community-based services

The majority of countries (n=16) reported that family advocacy groups are involved in making recommendations to home and community-based services caring for children with ADHD. Seven countries reported that family advocacy groups do not have this role and one country did not answer this question.

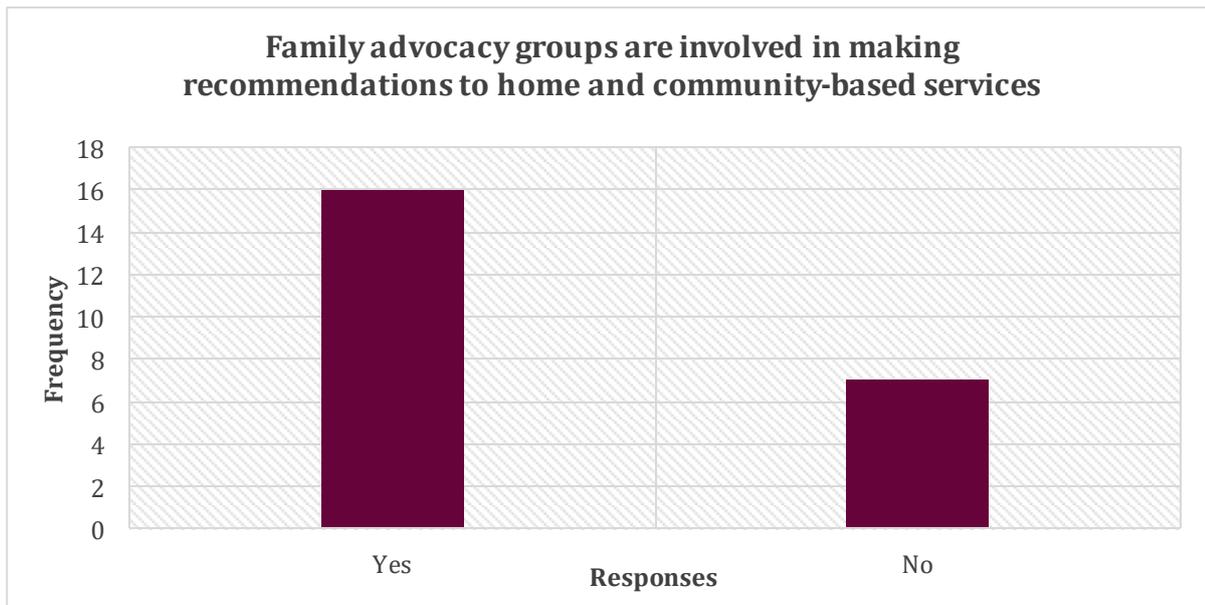
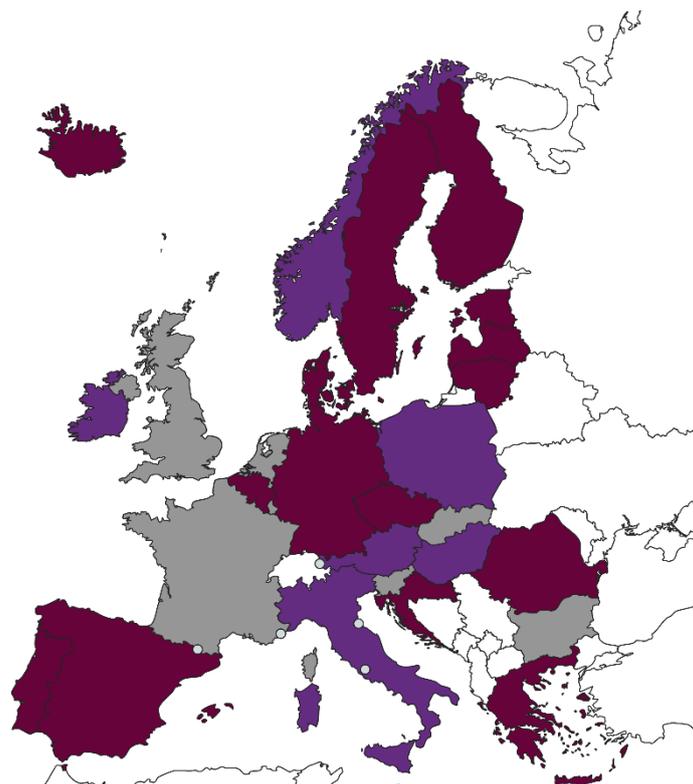


Figure 4.22: Family advocacy groups are involved in making recommendations to home and community-based services

**Family advocacy groups are involved in making recommendations to home and community-based services**

- Yes
- No
- No response
- Non-Mocha country



Map 4.6: Family advocacy groups are involved in making recommendations to home and community-based services

**4.1.4.3. The parents, guardians and siblings of children with ADHD have access to professional psychosocial support**

Nineteen of twenty-two countries reported that the parents, guardians and siblings of children with ADHD have access to professional psychosocial support. The five countries in which support was not available were Hungary, Italy, Latvia, Malta and Norway. It should be noted that in some of these cases, the families access psychosocial support by presenting at services independently of the child with

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ADHD, and their having a child or sibling with ADHD does not improve (or hinder) their ability to access psychosocial support.

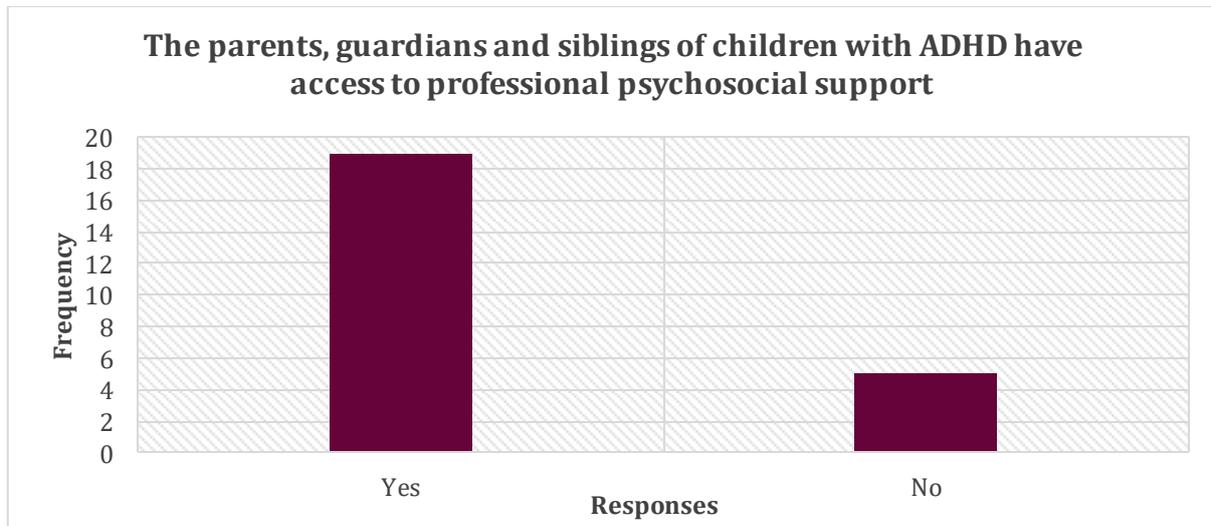


Figure 4.23: The parents, guardians and siblings of children with ADHD have access to professional psychosocial support

#### 4.1.4.4. Respite care is available for children with ADHD

Fourteen countries replied that there is respite care available in their country for children with ADHD and their families, but ten reported that there is no respite care available in relation to ADHD.

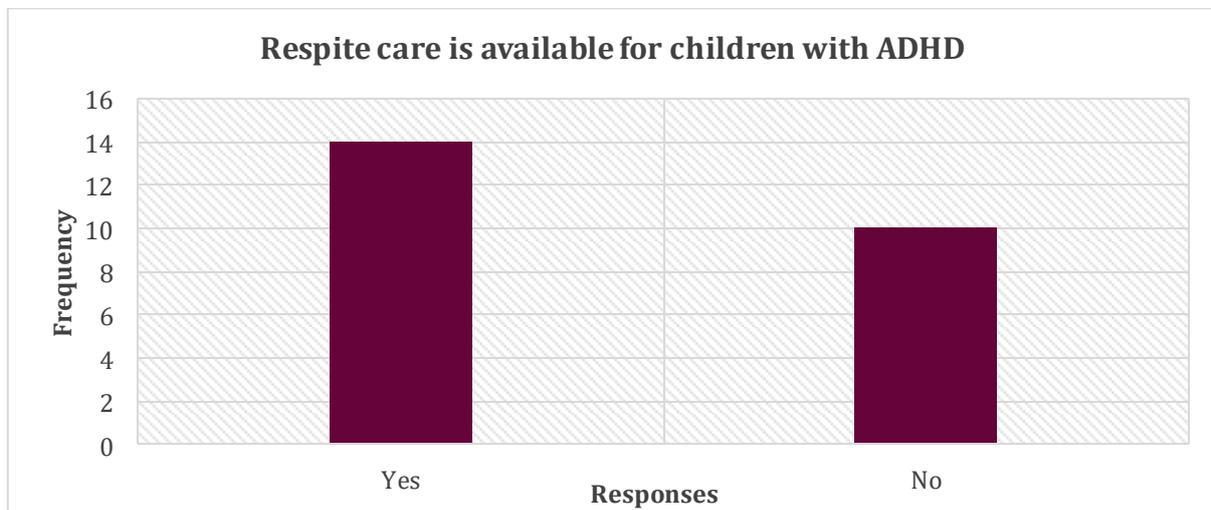


Figure 4.24: Respite care is available for children with ADHD

#### 4.1.4.5. Providers of respite care available for children with ADHD

Of the fourteen countries where respite care is available, ten countries reported that respite care for children with ADHD is provided by the state, voluntary sector and private sector.

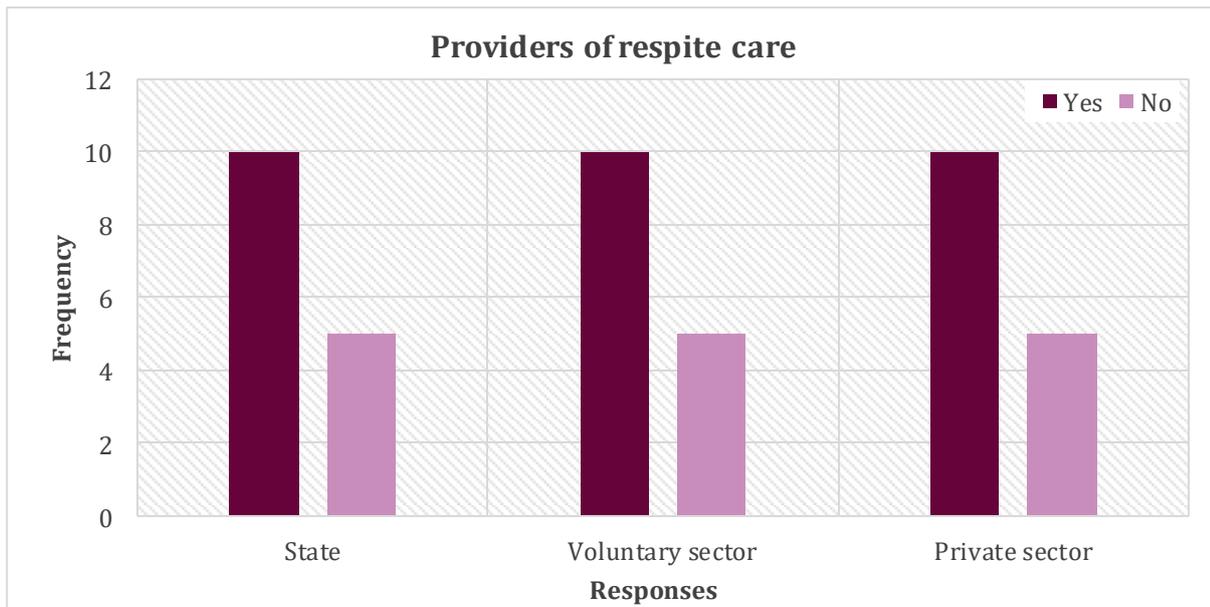


Figure 4.25: Providers of respite care available for children with ADHD

**4.1.4.6. Children with ADHD are offered the opportunity to acquire skills or education according to their individual needs**

Most countries (n=19) reported that opportunities to participate in education and training tailored to the individual are offered to children with ADHD, while three countries (Cyprus, Hungary and Latvia) reported that this not available.

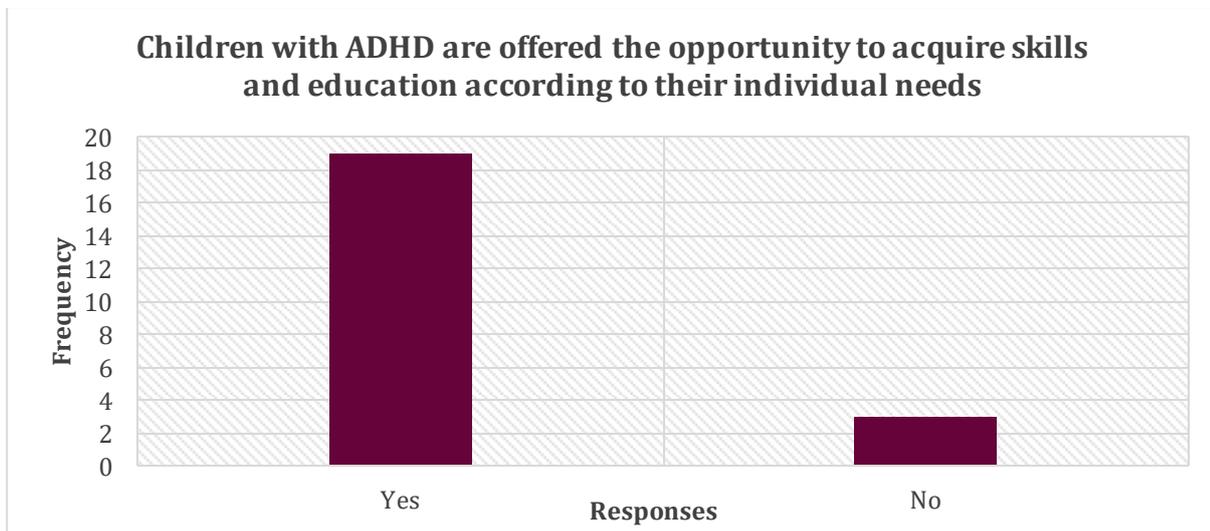


Figure 4.26: Children with ADHD are offered the opportunity to acquire skills and education according to their individual needs

#### 4.1.5. Family Professional Partnership

##### 4.1.5.1. Parents and guardians of children with ADHD are invited to participate in the development of policies and procedures affecting their children

Nine countries reported that parents and guardians of children with ADHD are invited to participate in the development of policies and procedures affecting their children, while fifteen said that parents were not involved in this way. One country did not answer.

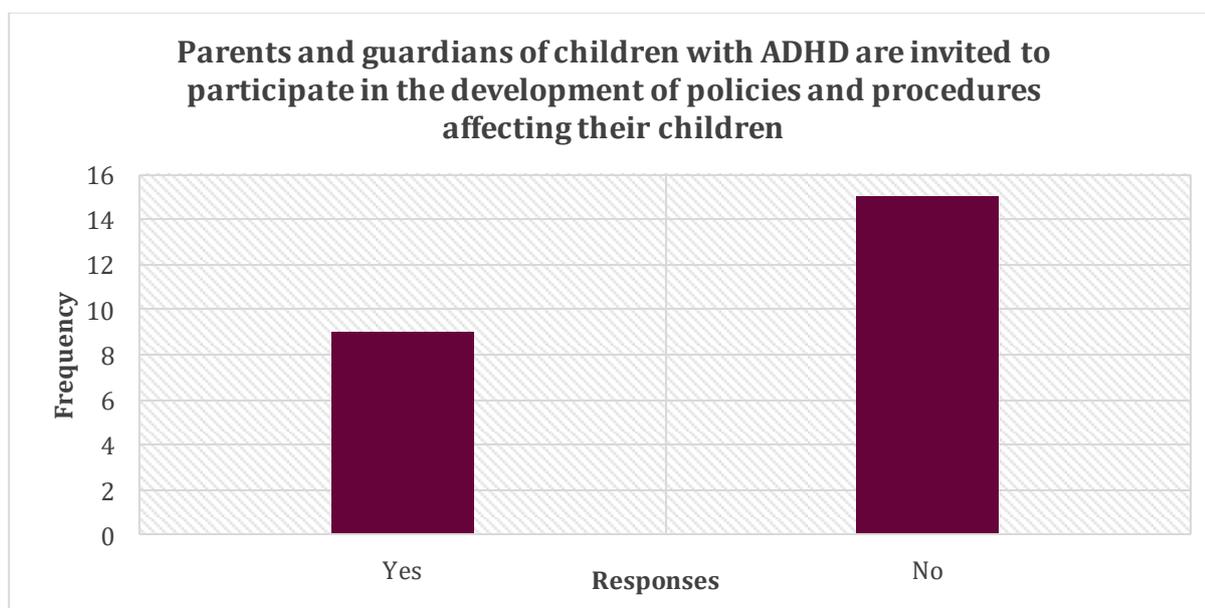


Figure 4.27: Parents and guardians of children with ADHD are invited to participate in the development of policies and procedures affecting their children

##### 4.1.5.2. Parents and guardians of children with ADHD are included in national quality improvement initiatives for ADHD

Only eight countries reported that parents and guardians of children with ADHD are included in national quality improvement initiatives for ADHD, but in seventeen countries they are not included in this way. One country did not answer.

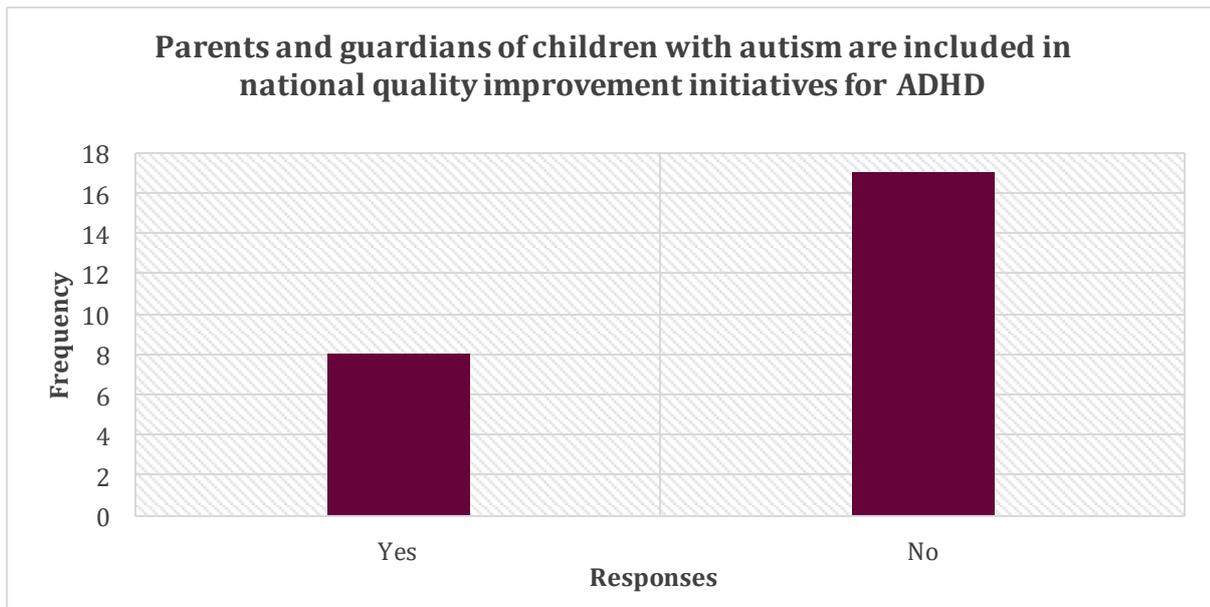


Figure 4.28: Parents and guardians of children with ASD are included in national quality improvement initiatives for ADHD

#### 4.1.5.3. Parents and guardians of children with ADHD review materials for the public regarding ADHD to ensure they are culturally or linguistically appropriate

Nine countries reported that parents and guardians of children with ADHD review materials for the public regarding ADHD to ensure they are culturally or linguistically appropriate, but in fourteen countries parents and guardians are not involved in reviewing these materials. Two countries did not answer.

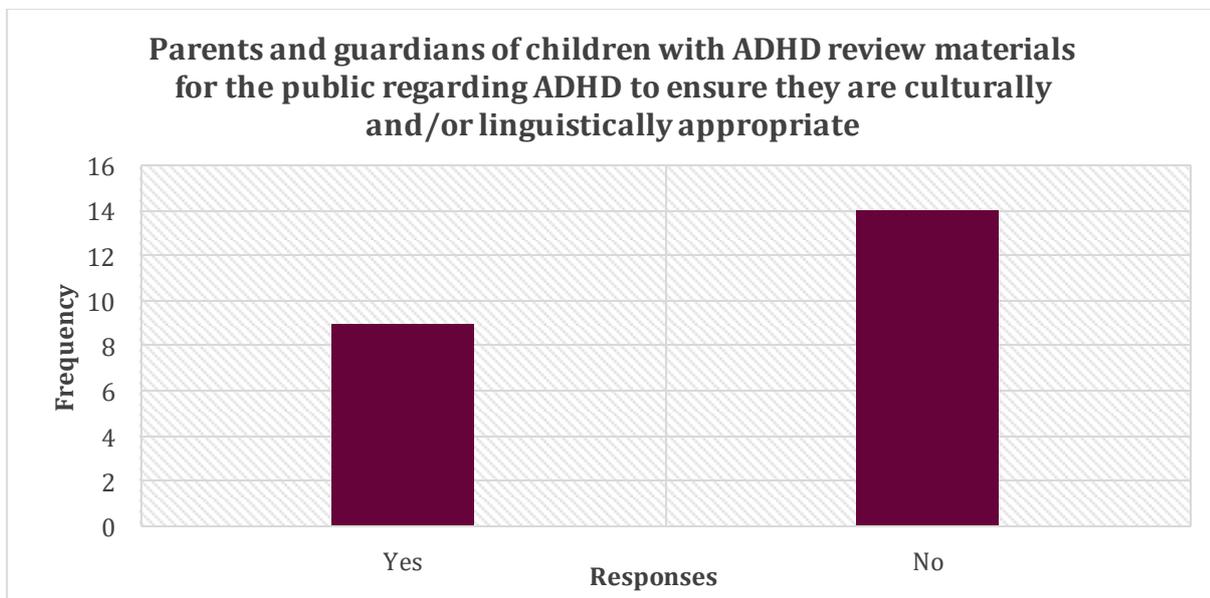


Figure 4.29: Parents and guardians of children with ADHD review materials for the public regarding ADHD to ensure they are culturally or linguistically appropriate

#### 4.1.6. Transition to Adulthood

##### 4.1.6.1. Policies or procedures to ensure continuity of care for adolescents with ADHD transitioning to adult specialists and community supports

The majority of countries (n=20) did not have policies or procedures to ensure continuity of care for adolescents with ADHD transitioning to adult specialists and community supports, and only five countries (Denmark, Estonia, Finland, Norway, UK) reported that they did have such policies or procedures.

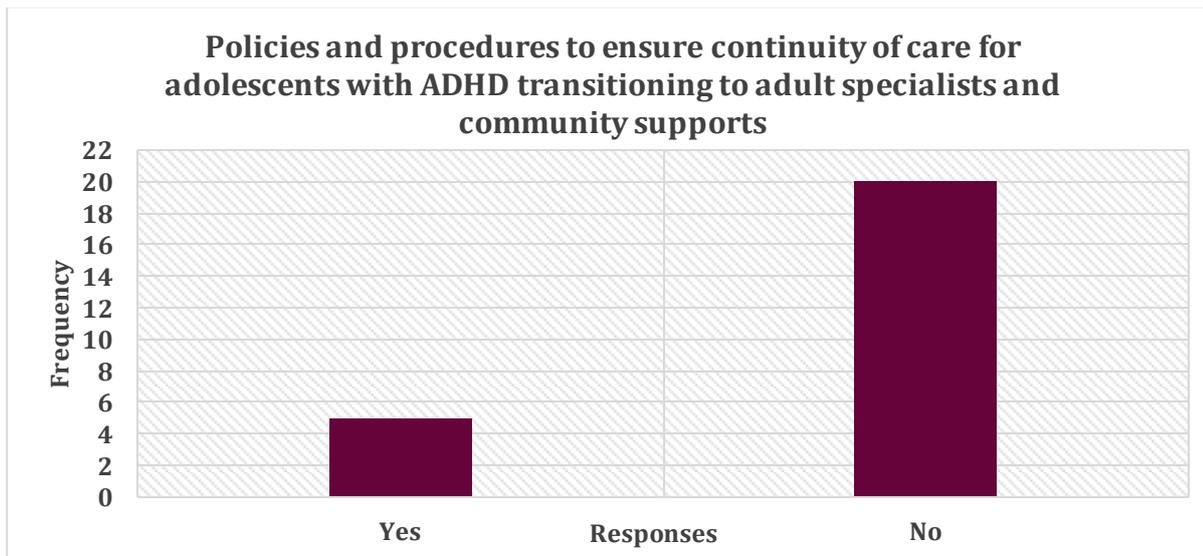
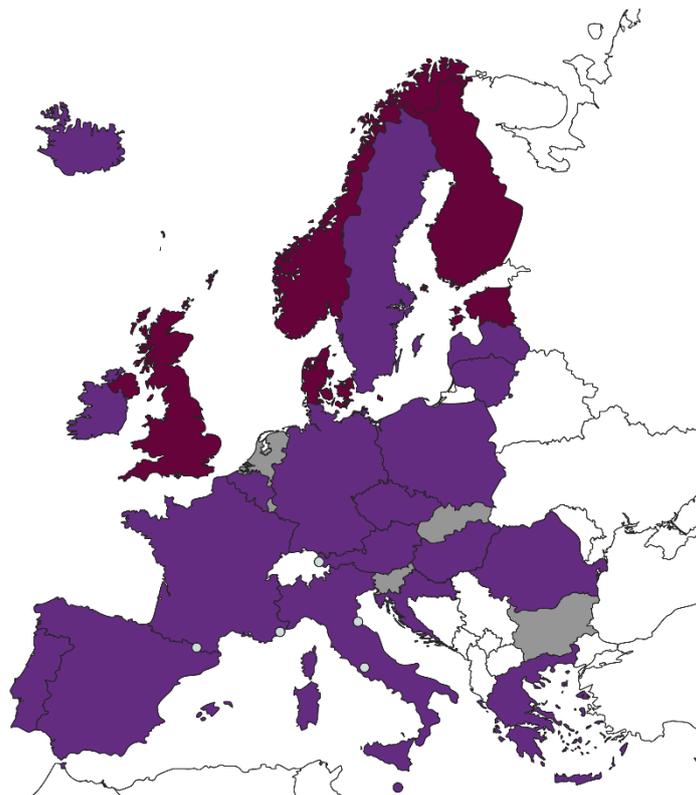


Figure 4.30: Policies or procedures to ensure continuity of care for adolescents with ADHD transitioning to adult specialists and community supports

##### Policies or procedures to ensure continuity of care for adolescents with ADHD transitioning to adult specialists and community supports

- Yes
- No
- No response
- Non-Mocha country



Map 4.7: Policies or procedures to ensure continuity of care for adolescents with ADHD transitioning to adult specialists and community supports

#### 4.1.7. Quality Assurance

##### 4.1.7.1. There are quality assurance policies or procedures for service providers caring for children with ADHD

Most countries (n=15) had neither policies nor procedures regarding quality assurance for service providers caring for children with ADHD. Four countries had quality assurance policies and procedures, one had policies only and one had procedures only. Answers were not available from two countries.

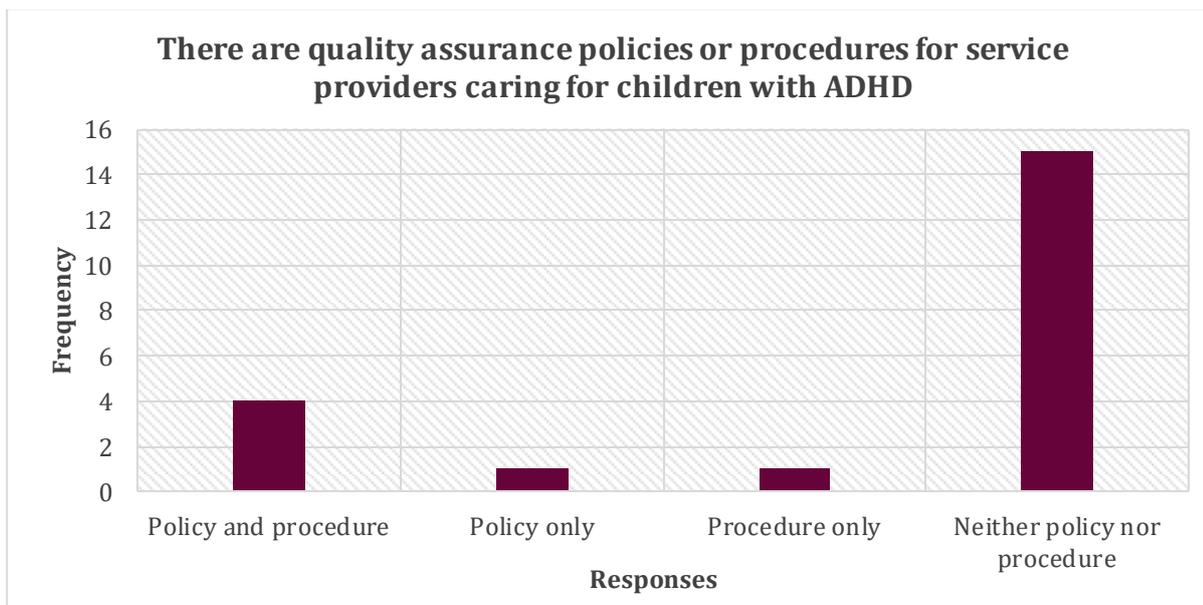


Figure 4.31: There are quality assurance policies or procedures for service providers caring for children with ADHD

##### 4.1.7.2. Perspectives of data collected regarding the experience of care for children with ADHD

In most countries, data regarding the experience of care for children with ADHD is not collected. Five countries reported that data is collected regarding the experience of care for children with ADHD from the perspective of the parents and in one country from the perspective of the siblings. Primary health and social care professionals provide data regarding the experience of care for children with ADHD in four countries. One country did not respond to this item.

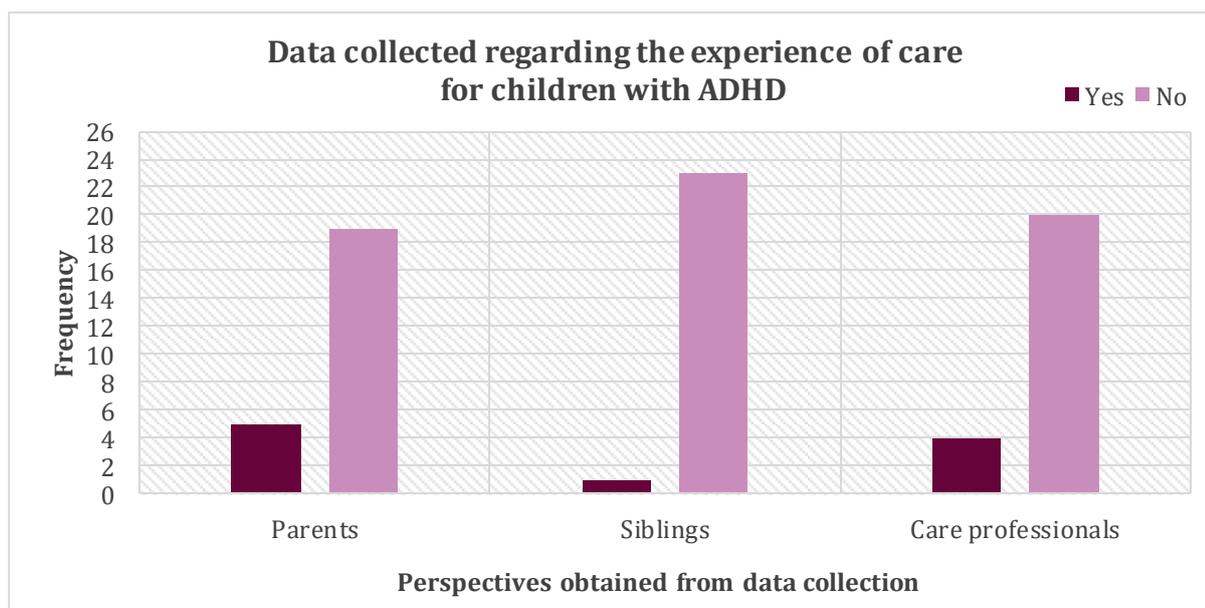


Figure 4.32: Perspectives of data collected regarding the experience of care for children with ADHD

#### 4.1.8. Summary of key results in the management of care of children with ADHD

- Fewer than half of responding countries reported both policies and procedures to ensure preventative care screening and developmental checks or communication of results with care providers and parents.
- More countries had policies and procedures that identified named healthcare providers and experienced consistency in their treatment teams than those in the social care system
- Formal training is offered to parents in most countries, but only a minority have procedures to ensure parents have the capacity to integrate the training into daily life.
- Primary care can be accessed regardless of the care given in secondary care in the vast majority of countries.
- Care coordination was promoted via written regulation in around a third of the responding countries and a hospital discharge coordinator was provided in around half of the countries.
- There were reports of policies and procedures being in place regarding specific care pathways for ADHD, but a number also reported having partial pathways, some of which described the roles of each care provider and aimed to integrate primary and secondary care.
- Around half of countries reported policies ensuring a written personalised plan, but of these, most consulted with parents, healthcare and social care professionals and integrated many aspects of care. Four countries indicated that written personalised plans are commonly made for children with ADHD although there are no policies to enforce this.
- More than half of countries reported that community-based services were key, endorsed the importance of the availability of respite care and supported the establishment of family advocacy groups that could make recommendations to community-based services.
- Parents were engaged in the development of policies, procedures and national quality initiatives to some extent.
- Policies and procedures were lacking around assessments of family competencies in providing care, transitions between adolescent and adult care, provision of culturally or linguistically appropriate information, quality improvement and patient experience data.

## 4.2. Business models of care for children with ADHD

A business process model approach was used to identify the actors and collaborations who provide health and social care preventive screening and developmental checks (questions 1.2b and 1.2c) and develop and implement the written personalized plan (questions 3.3a-c).

### 4.2.1. Provision of preventive screening and developmental checks

#### 4.2.1.1. Use case diagram

The UML use case diagram depicted in Figure 4.33 provides a static description of the activities related to the provision of health and social screening services mirroring the relevant questions of the questionnaire. Considering the provision of health care screening (“*Provide health care screening*” use case reported in the upper-left part of the diagram) one team has been identified (depicted in the figure with the UML composition symbol ):

- A Secondary and Primary care Team composed by both mental health and primary care professionals (Czech Republic).

In the majority of countries, health screening is performed by individual professionals belonging to primary care and mental health not working in team (Croatia, Cyprus, Hungary, Latvia, Lithuania, Poland, Portugal, Romania and Spain, as depicted by the dotted line). In Germany, school professionals are also present, along with primary and mental health professionals (but not working in a team). In Italy and in Malta, health screening is performed by mental health professionals.

Considering the provision of social care screening (“*Provide social care screening*” use case in the lower-left part of the diagram), in several countries this activity is performed by a social worker (Croatia, Malta, Romania, Spain). In Hungary and Italy, the family physician is also involved, while in the Czech Republic, Germany, Latvia, Lithuania, Poland and Portugal the school professional may perform this activity, but not working in team. Secondary and social care professionals are present in Cyprus, even if not in a team.

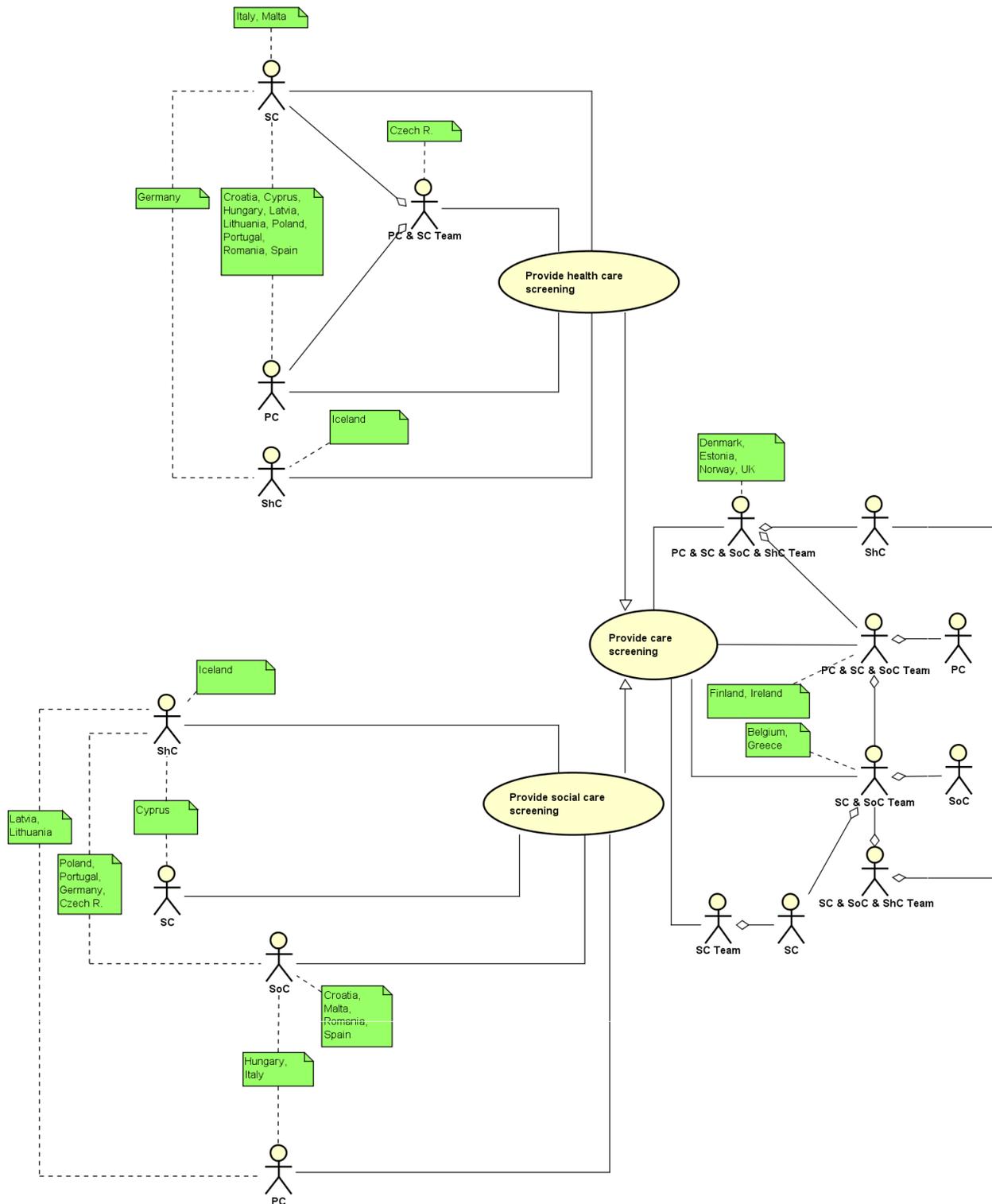
In a limited number of countries this activity is organized in a more collaborative way, with the following team compositions:

1. A professional collaboration comprising secondary, primary, social and school professionals is present in Denmark and Norway (within the municipality) as well as in Estonia and the UK. In Finland and Ireland, this professional collaboration does not include the school component.
2. A mixed team composed of mental health and social professionals is present in Belgium and Greece.

In Iceland, screening for educational issues is performed in schools and if there are concerns, the child is referred to the school specialist centre.

Regional differences were mentioned in many countries. For instance, in Portugal at the Paediatric Hospital Dona Estefania (Lisbon) a special prevention and promotion programme for ADHD children was developed, which foresees a multidisciplinary collaboration among family physicians, mental health professionals, social workers and school.

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PC = Primary care professionals; SC = Secondary care; SoC = Social care; ShC = School care; MoM = Member of the municipality

Figure 4.33: UML use case diagram: provision of screening services

#### 4.2.1.2. Maps

A summary of the results described in the UML use case diagram is shown in the maps reported in the following figures (see Figure 3.34 for the provision of health screening and Figure 3.35 for the provision of social screening) where countries that feature professional collaboration are reported in both maps in dark violet.

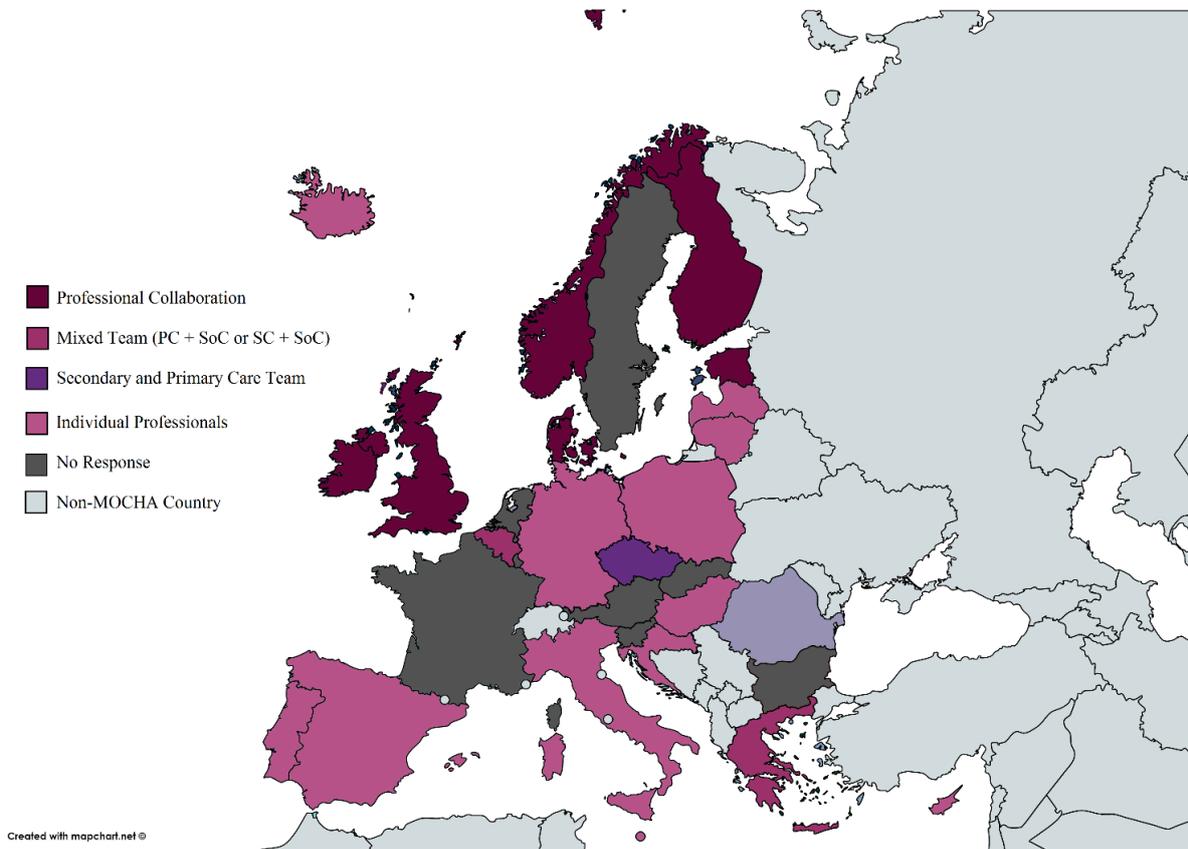


Figure 4.34: Provision of health care screening

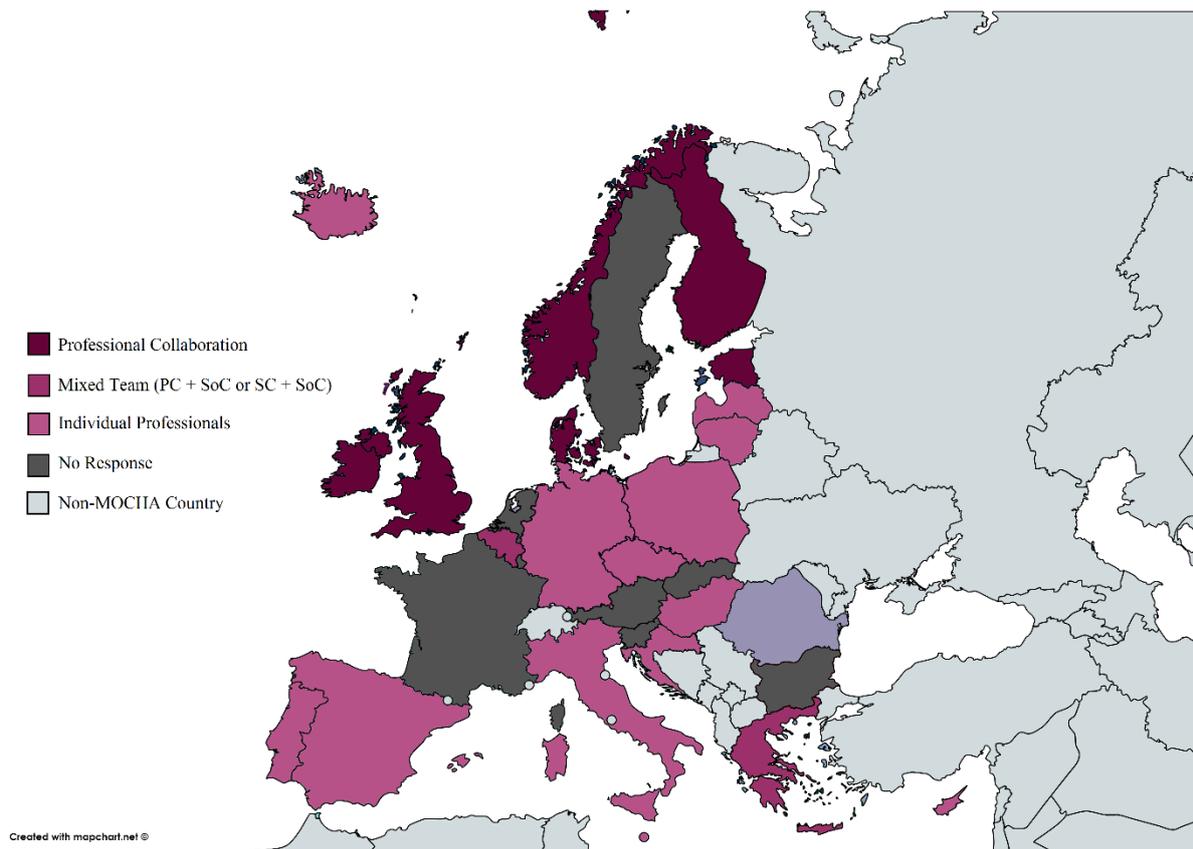


Figure 4.35: Provision of social care screening

## 4.2.2. Development and implementation of the personalised plan

### 4.2.2.1. Use case diagram

The UML use case diagram depicted in Figure 4.36 provides a static description of the activities related to the development and the implementation of the personalized written plan.

Considering the development of the plan (“*Develop the personalized written plan*” use case) the following teams have been identified (depicted in the figure with the UML composition symbol  $\diamond$ ):

1. A professional collaboration among primary, secondary and social care professionals forming a multidisciplinary team (Finland, Ireland and Norway). In Denmark and the UK, the team also includes school professionals. In the UK in particular, a special educational needs co-ordinator (SENCO) initiates and is in charge of the written personalised plan.
2. A mixed team composed of mental health and social care professionals (Greece). In Estonia, this team also comprises school care professionals.
3. A care team composed by mental health professionals is present in Germany.

Other actors are involved in this activity as individual professionals but not working as members of the team. These actors belong to the health care setting: primary care professionals (Croatia and Portugal), secondary care professionals (Cyprus, Czech Republic, Hungary, Malta and Romania), or

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both (Italy, Lithuania and, without policy or formal procedure, Poland), even if not in a team. In Iceland the plan is developed by the school specialist centre.

Regarding the implementation of the plan ("*Implement the personalized plan*" use case) the following teams have been identified:

1. A professional collaboration among primary, secondary and social care professionals forming a multidisciplinary team (Finland, Ireland and Norway). In Denmark and the UK, the team also includes school professionals. In the UK in particular, a special educational needs co-ordinator (SENCO) starts and is in charge of the written personalised plan.
2. A mixed team composed of mental health and social care professionals in Greece, and with the addition of school professionals in Estonia.
3. A care team composed of mental health professionals is present in Germany.

In the other countries, the implementation of the personalised plan is performed by individual health care professionals in primary care (Croatia and Portugal), secondary care (Cyprus, Czech R., Hungary, Malta, Poland and Romania), or both, even if not in a team (Italy and Lithuania). In Iceland, the plan is developed by the school specialist centre.

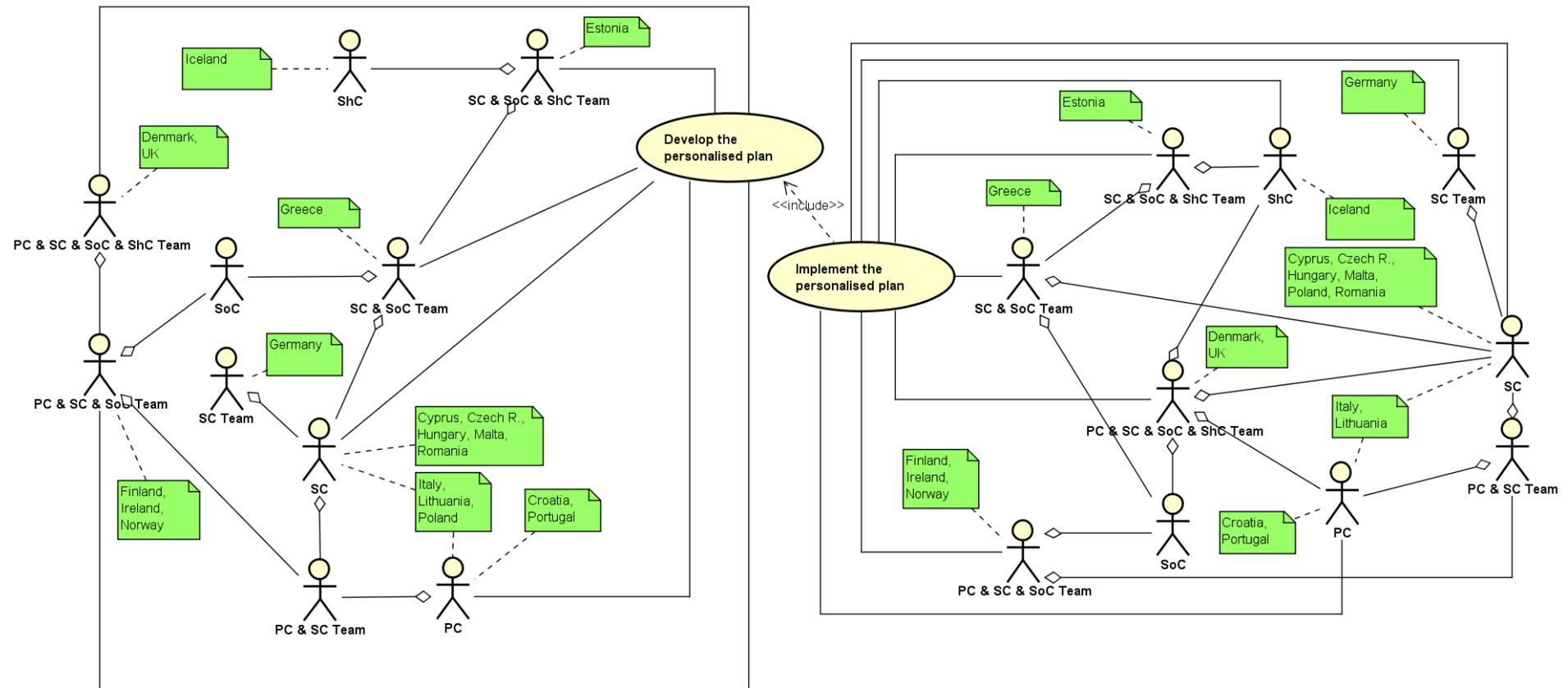
Similarly to autism, in countries where there are professional collaboration or mixed teams that develop a personalized care plan, the implementation of the plan is carried out by the same team.

Some CAs (e.g. Portugal, Romania, Spain) reported that there are regional differences within countries and this also influences the composition of professionals carrying out these activities. Moreover, the composition of the team may also depend on the severity and/or on pharmaceutical treatment (cf. Danish response).

#### **4.2.2.2. Maps**

A summary of the results described in the previous paragraph is shown in the maps reported in the following figures (see Figure 4.37 for the development of the plan and Figure 4.38 for the implementation of the plan). Note that countries that feature professional collaboration in both activities are reported in the maps in dark violet.

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PC = Primary care professionals; SC = Secondary care; SoC = Social care; ShC = School care; MoM = Member of the municipality

Figure 4.36: UML use case diagram: development and implementation of the personalised plan

## Requirements and models for supporting children with complex mental health needs and the primary care interface

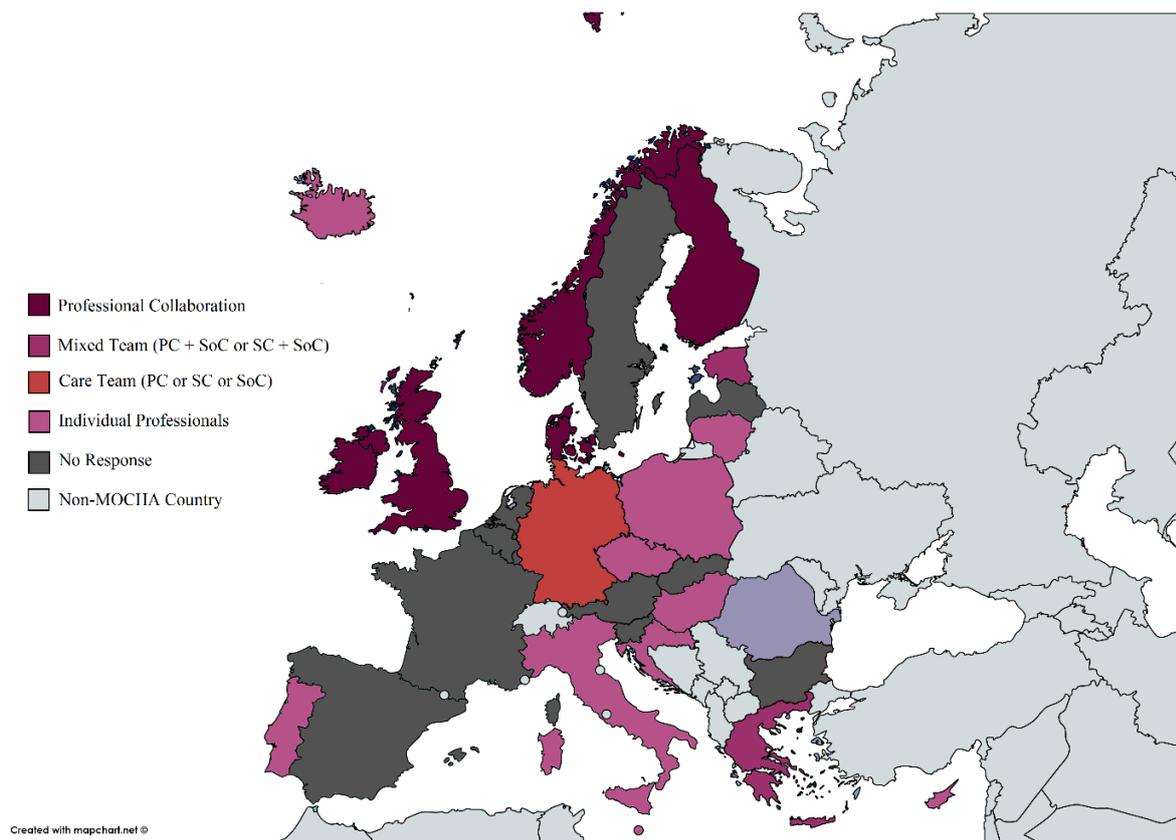


Figure 4.37: Development of the personalized plan

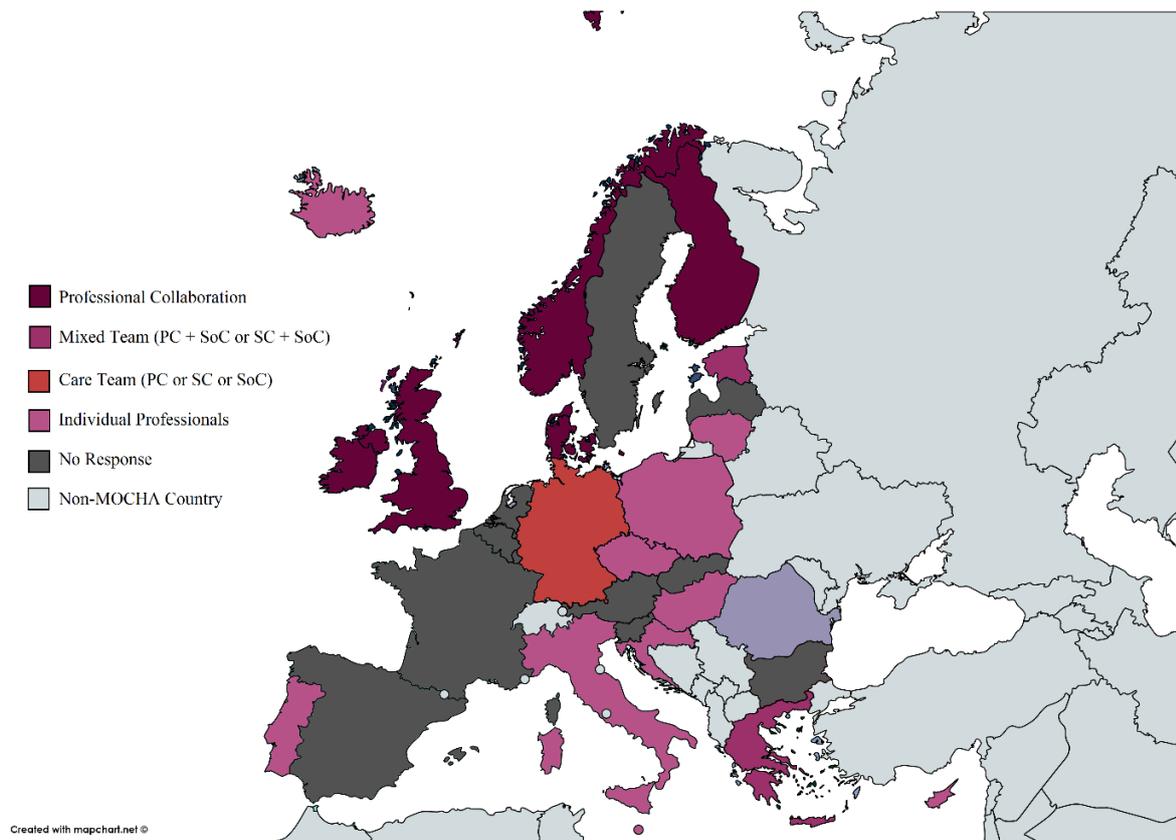


Figure 4.38: Implementation of the personalized plan

### 4.2.3. Key findings

- In the majority of countries, the whole range of activities (screening, development and implementation of the plan) is performed by individual professionals not working in a team.
- In the Scandinavian countries, a crucial role is played by municipalities where formal professional collaboration is present for both the development and implementation of the plan. Similar team composition (Ireland and UK) facilitates the continuity in the performance of screening services as well as in the development and implementation of the plan.
- Considering the social aspects of the child's care, the best pattern of collaboration includes social workers and school care professionals, but this is implemented in a minority of countries. However, teacher and school services play an important role in the detection of early symptoms of ADHD and this is reported by many CAs as a first step to refer the child to the appropriate services.

A table summarising findings can be found in *Appendix 6*.

### 4.3. Facilitators and barriers to integration of primary and secondary care

Country Agents were asked to provide qualitative comments as part of the survey, which were subjected to a thematic analysis [30]. Three Global Themes emerged from the data: “family as partners in care,” “access to appropriate care” and “care coordination.” “Family as partners in care” highlights the need for supports for parents and the recognition of the shared responsibility between the family and professionals. “Access to appropriate care” emphasises routes to secondary care and the availability of specialists as key to the appropriateness of the care, as well as sufficient service resources. “Care coordination” describes the importance of receiving coordinated, individualised, team-based care that engages with community-based services and is defined by legal structures.

The connections between the Global Themes suggest that access to appropriate care and support of the family as partners in care are complementary and brought together by comprehensive care coordination. The data suggest that these three main factors may contribute to optimal care of the child with ADHD at the primary/secondary interface.

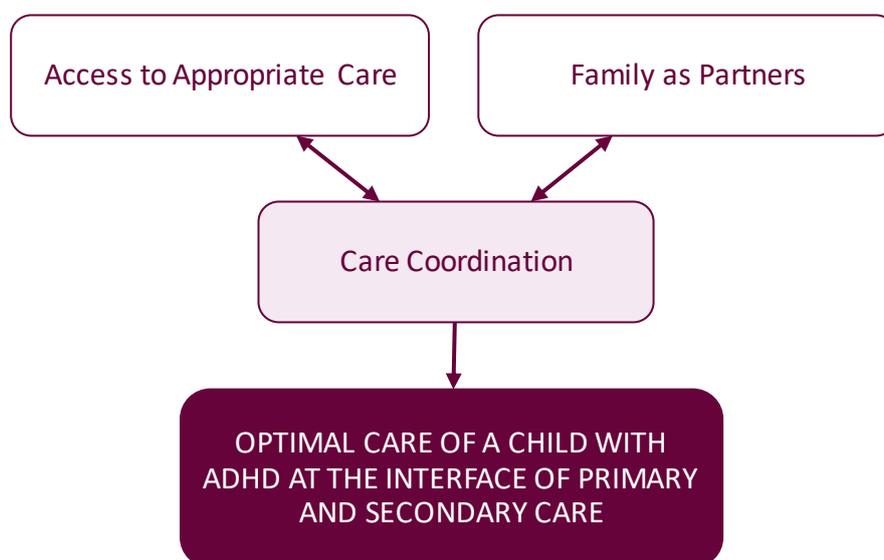


Figure 4.39: Global themes at the interface of primary care for children with ADHD

This section also includes insights from the DIPEX study, which produced convergent and complementary findings regarding the process of getting a diagnosis, training for GPs, the coordinating role of parents, continuity of the care team and the role of the school.

#### 4.3.1. Access to appropriate care

The Global Theme “access to appropriate care” involves the availability of specialists with appropriate knowledge and expertise, access to secondary care through developmental screening, suitable care of comorbidities and universal primary care. Some services are suffering from inadequate resources.

#### **4.3.1.1. Routes to secondary care**

##### ***Childhood development screening***

In every country, children undergo developmental screening and assessments in order to monitor their growth and identify health conditions, including developmental and sometimes behavioural, disorders. This may lead to referral to secondary care for further assessment, diagnosis and specialist care, for example:

*“Every year each child (despite what disease he has) has to undergo prophylactic health check. It has to be done by a family physician or paediatrician working in primary health care. And he decides to which specialists to refer the child for secondary consultation.” (Lithuania)*

However, the current screening process does not always specifically include ADHD, potentially delaying diagnosis for some children.

*“Developmental disorders should be more closely part of the examinations of the Mother-Child Pass. Now it is voluntary if these kind of examinations will be done or not. One can say that the screening ADHD assessment is full of gaps.” (Austria)*

*“The Ministry of Health does not have a policy for preventive care screening for children especially for ADHD, as it is mentioned for Autism” (Romania)*

In the majority of countries, children with an ADHD diagnosis continue to receive thorough developmental screening like their peers, although screening for mental health comorbidities may be lacking.

*“There is no specific screening for MH comorbidities. Depends on the qualification of the specialist providing care.” (Latvia)*

This may mean relying on the inclination or awareness of the clinician to screen for comorbidities outside the requirements of the screening programme.

##### ***Gatekeepers in primary care***

In many countries, access to primary care is necessary to access secondary care, since GPs and paediatricians function as gatekeepers, making referrals to the appropriate specialists. In this respect, free universal healthcare was cited as a facilitator to accessing primary and secondary care. In addition, primary care may also be responsible for some elements of care and follow up, including monitoring children’s response to medication and renewing prescriptions, for example:

*“The first prescription is initiated by a specialist in the disorder (paediatrician, paediatric psychiatrist, neuro-paediatrician, neurologist) but can then be renewed by the general practitioner.” (France)*

##### ***Care of comorbidities***

Comorbid mental health and developmental disorders are extremely common with ADHD and it is critical that the child receives care relating to both their ADHD and their comorbid conditions.

*“It is very important to recognise ADHD and its comorbidities. ADHD has to be treated as well as the comorbidities. According to the child and its diagnoses, separated or combined treatments should be provided but ADHD-specific therapy elements have to be included.” (Germany)*

Good care for comorbidities would be tailored to their needs, integrated into their existing specialist care, e.g. within CAMHS or by their current specialist team, and coordinated appropriately between services:

*“Children with ADHD and comorbid conditions are cared [for] in the specific services according to the nature and severity of the comorbidities ... this is an important issue. Some hospitals have good coordination between paediatric and child psychiatric services.” (Portugal)*

A number of countries reported that comorbidities are cared for as distinct from the care for ADHD, leading to potential difficulties:

*“There are no special separate procedures for children with ADHD [to] care [for their] comorbidities – and if the child needs such care, it is always a problem for parents to bring the child to primary or secondary healthcare centres and wait, for example, in the queue.” (Lithuania)*

#### **Insights from DIPEX: Process of getting a diagnosis**

When seeking a diagnosis, GPs were often gatekeepers to specialist services, although in the Czech Republic this was not necessary and was reported as helpful. Some parents perceived that their concerns were not taken seriously by GPs, who were dismissive and did not accept ADHD as a “real” condition, particularly in Germany. Some parents reported looking for alternative doctors who would respect their concerns.

Once referrals were made, the process was lengthy and difficult, with multiple appointments for different tests in locations that might be far from their homes. Parents reported feeling overwhelmed, helpless and stressed by the complexity of the process and having to wait a long time to receive help for their children. Parents in the UK were dissatisfied with the short duration of the appointments and frustrated with multiple visits in which they felt no progress was made.

*“Now we wanted to know what the deal was. We took the whole vacation time to do the complete diagnostics. This proved to be extremely difficult, because the diagnostic of the whole physical part we knew, but there were also all the interviews etc. for the psychological part. We thought during the school holidays we would be finished. We as parents needed to be very persistent to get the appointments in different hospitals we needed, for example for an EEG or for the cardiogram. For this we needed to go to another city that was 30 kilometers away, only to get one appointment for the doctor, who could do the cardiogram. Not the child cardiologist, those seem to be very rare. I’m not sure, but the clinics seem to be very overbooked. I called one and I have been told we need to wait about nine months.” (G, F, parent)*

#### 4.3.1.2. Availability of specialists

##### **Specialists and expertise**

A major barrier to safe and efficient care for children with ADHD is a shortage of specialists. This includes paediatric and adolescent psychiatrists and other mental health professionals (e.g. Austria, Estonia, Latvia), as well as specialist social care providers (e.g. Czech Republic, Hungary, Lithuania). In some countries, roles or services providing care for children with ADHD may not exist, or they may exist and be understaffed. For example, in France, no organisations provide ADHD-specific care, and in Portugal, children with ADHD are cared for in primary care only:

*“In my country, in primary care there are no specific services for ADHD. The child will be cared (for) within primary care health services.” (Portugal)*

In other cases, professionals may be working at the limits of their capacity:

*“Workload in psychiatric services is high and sometimes specialists have trouble finding time for additional meetings or discussions [with parents].” (Estonia)*

In some countries, mental health nurses and paediatricians can receive specific education in caring for children with ADHD.

##### **Gaps in knowledge**

The scarcity of relevant specialists is mirrored by the significant knowledge gaps outside of secondary care. For example, in Lithuania community-based healthcare is provided by:

*“mostly family physicians/GPs or primary care paediatricians (but most of them have very little knowledge about the treatment of such kids).” (Lithuania).*

Similarly, the respondent from Romania remarked on the lack of specialists outside urban centres and recommends that guidelines be introduced to assist primary care physicians:

*“Because [of ADHD’s] complexity, it is hard to diagnose by family doctors or other medical doctors (especially in places without a psychiatric specialist, which is often the case in small towns and in rural areas) and is therefore underdiagnosed. It would be useful to have a national protocol in recognising the signs of ADHD and make the referral to a specialist.” (Romania)*

More training regarding ADHD is required to ensure good understanding among professionals and how they can collaborate with families:

*“Big lack [in family-professional partnership] caused by deficit of consciousness and knowledge about specific requirements of this illness.” (Austria)*

##### **Healthcare providers included in responses:**

- General Practitioner
- paediatrician
- psychiatrist
- psychologist
- psychotherapist
- paediatric neurologist
- community children's nurse
- health visitors/visiting nurse
- school nurse
- physiotherapist
- primary care dentist
- speech and language therapist
- geneticist
- occupational therapist

Figure 4.41: Healthcare providers included in responses

### ***Specialists for adult care***

The insufficiency of paediatric and adolescent specialists for ADHD is intensified among care for adults with ADHD. Almost half of responding countries commented on the lack of services for adult ADHD or lack of awareness among healthcare providers that ADHD can even continue into adulthood. Further, as the children with ADHD diagnoses grow up, there is an increasing demand on adult services. A particularly thorough answer regarding barriers to continuity of care when transitioning to adulthood was provided from Germany, and supported by a number of other countries:

- *“Lack of knowledge about therapeutic possibilities*
- *Lack of access to therapists*
- *Too long driving times to therapists*
- *ADHD is often diagnosed incorrectly in adulthood because of a lack of professional expertise*
- *Widespread view that ADHD will disappear in adulthood*
- *Some specialists take ADHD for a ‘mode-diagnosis’ (fashionable)” (Germany)*

### ***Insights from DIPEX: Training for GPs***

Parents were sceptical about their GP’s knowledge and understanding of the children’s conditions and as a result, rarely visited the GP. GPs often initiate referrals for diagnosis and in that way, play a critical role in the child’s care. However, participants felt that the GP’s lack of knowledge delayed the diagnostic process as they do not have the necessary skills to recognise mental conditions.

Parents felt that GPs should be aware of how these conditions are treated in secondary care and parents in the UK felt that it would be helpful to have more GPs with specialist knowledge in ADHD. Children in Germany perceived that the GP was not knowledgeable about ADHD or qualified enough to treat their condition. One parent in the Netherlands reported trusting the GP more because she was aware he had received further training and was more knowledgeable.

*“My GP, yes, I think he is really good. I know that they are doing a lot of further education. I know that in the practice, especially the male GP of the duo, did a course on ADD, on medication. Things like that. He really has knowledge about it. So, I trust him based on his knowledge” (ID52,NL, F, parent)*

### **4.3.1.3. Service resources**

In many countries, there are long waiting lists for care of children with ADHD, preventing children from receiving care in an appropriate timeframe:

*“The results of the (audit) indicated that 29% of children suffering from activity and attention disorders received medical care on time.” (Estonia)*

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This has been linked to staff shortages, insufficient financial resources and a lack of political awareness and will:

*“At ministerial level there is also a lack of recognition of the number of children who deal with ADHD and related conditions/problems. This has led to a long-standing lack of funds/financing and long waitlists at all levels.” (Iceland)*

The inadequacy of resources in relation to ADHD services has been reported as hindering access to care in general, but also as a barrier to moving between primary and secondary care and experiencing continuity of care.

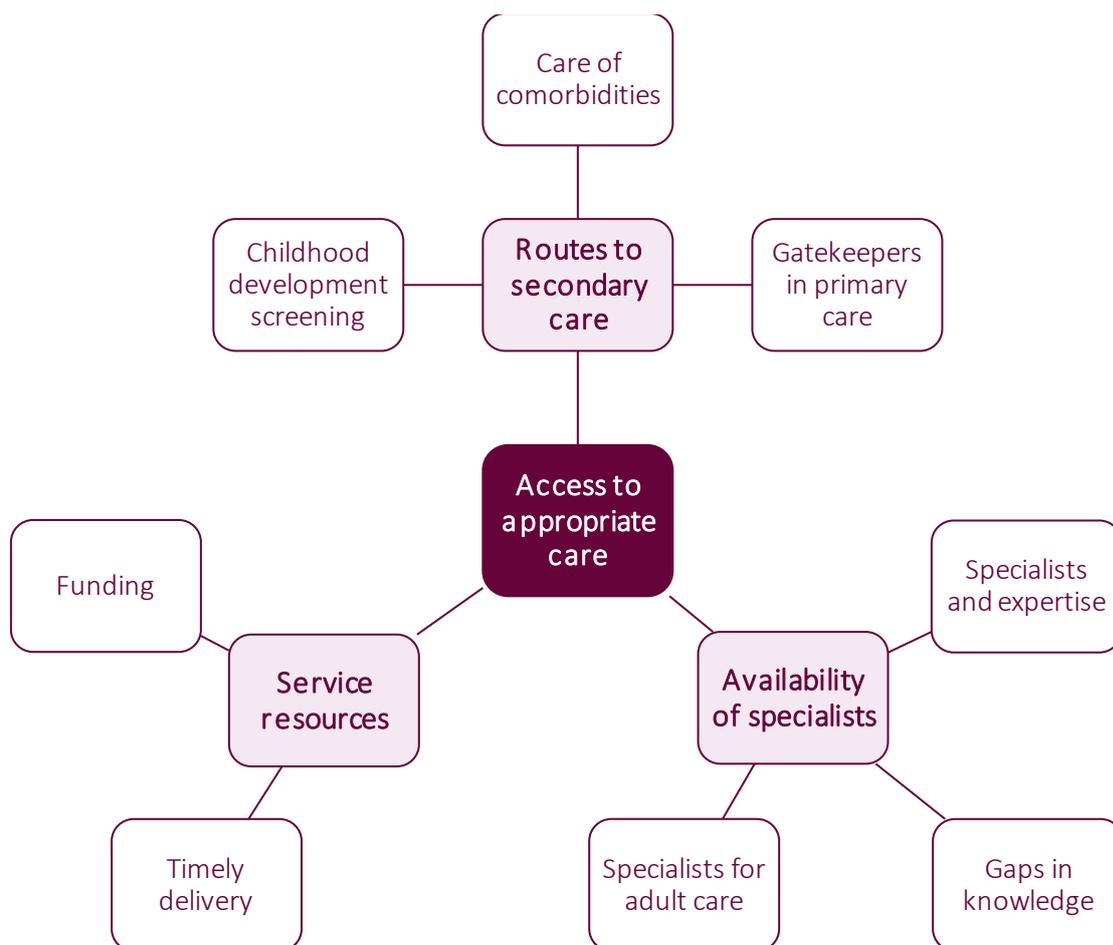


Figure 4.420: Emergence of Global Theme “Access to appropriate care”

### 4.3.2. Family as partners in the child’s care

The Global Theme “family as partners” describes the importance of the family-professional partnership in providing optimal care at the interface of primary and secondary care for a child with ADHD, as well as, more generally, the importance of the role of the family in caring for a child with ADHD. The integration of the family into the care, supports for the family and communication with the family were identified as organising themes.

#### **4.3.2.1. Shared responsibility of parents**

##### ***Integration and support with coordination***

Collaboration between the parents and the healthcare providers is seen as a facilitator of good care at the interface of primary and secondary care:

*“Cooperation between health care providers and parents facilitates the continuity of care and improves results.” (Estonia)*

In a number of countries, parents are involved decision-making and the development of the child’s care plan, but in others, the partnership between the healthcare professionals and parents is more all-encompassing, to include parental attitudes, for example.

*“The professional is focused on the involvement of the family, promoting appropriate parental attitudes towards the children’s needs.” (Portugal)*

*“Parents are an important part in the therapy of the children. Parents and guardians are integrated in the treatment as far as possible.” (Germany)*

However, in some countries such as Austria and Lithuania with no formalised care coordination, this responsibility is placed wholly with the parents. For example, in the case of hospital discharge after an acute behavioural episode:

*“The health professional suggests courses of action that the child should follow after discharge in order to receive health care. But the coordination and responsibility of following these recommendations lies with the child’s parents/guardians, not the discharge provider.” (Greece)*

The centrality of the role of parents in the care for children with ADHD can be difficult to manage:

*“Families often feel abandoned by professionals. Even when assessed, ADHD is difficult to control and parents are often overwhelmed by educational difficulties and children’s challenging behaviour.” (Romania)*

The challenges experienced by parents when they are not integrated into the child’s care and treated as partners point to the need for comprehensive supports for the families of children with ADHD.

##### ***Training for parents***

As well as the role of parents in care coordination, the relationships between the family and the child are central to supporting a child with ADHD and managing their behaviour. In most countries, parents are offered psychoeducation regarding their child’s ADHD and/or some form of training programme, such as the Incredible Years or Triple P (Positive Parenting Programme), e.g. Denmark, Estonia, Ireland, Norway. These programmes focus on:

*“developing positive parenting strategies, building effective communication strategies, and developing coping skills in parents and children.” (Ireland)*

The importance of these programmes presupposes the parent as an active partner in the child's care:

*"There is a special part (in the guidelines) about training and counselling children with ADHD, with their parents playing a practical part in the psychiatric team." (Estonia)*

### **Fee-based services**

The burden on parents to manage all of their child's care is exacerbated when the parents must seek fee-based services. This is the case in Lithuania, for example:

*"If parents have enough money, the child can be perfectly treated. But if the family has no money, these children will receive minimum support (only free services – means-funded by the government)." (Lithuania)*

### **Insights from DIPEX: parents as coordinators**

Parents of children with ADHD considered it important that their GP is well-informed about their child's condition. Some participants reported that they were responsible for bringing medical reports between specialists and their GPs and others that the clinicians communicated with each other. Some parents expressed their difficulties ensuring the health professionals inform each other about their child's care and others mentioned numerous stages when completing tests, for example. Parents reported feeling overwhelmed at times and that receiving the right treatment was time-consuming due to the number and distance of appointments. Parents in the UK articulated the need for a "road map" or pathway of services that they could access, as they found it difficult to find out which specialists were available, where they were located and how to access them. Parents in the Netherlands would also appreciate a social care professional or assistant to help them arranging care after discharge from hospital. Participants in the UK said they would benefit from support for parents, such as counselling, and more psychoeducation about ADHD.

*There's no pathway, there's no road...there's no kind of, right OK we're coming under this umbrella; there's loads of things we could be looking at. If we go down this road, these are the services you can go down. Go down this road; these are the services. Like if you don't go down this road, then this is all you're going to be able to go down in to connect to. And then you kind of, I guess have a head at certain points when certain things start coming out and they're growing up and they're changing and you see more of one side than another and all the rest of it. If you kind of know that there is this pathway, like maybe we need to start considering that because that's the only way we're going to get to get that other service, then it would just make you think a few steps ahead of yourself, which is instead of ending up at this place and you're in desperate need and then someone goes, 'Well actually if you were thinking about this we could access to that.' And it's like, 'Well if you'd told me that six months ago we could have started that process and got into line and got all our paperwork ready for whatever.' (UK, F, parent)*

#### 4.3.2.2. Supports for parents

##### **Needs assessments**

Often, parents' capacities to provide appropriate care for a child with ADHD are assessed in order to identify their challenges and support needs, followed by assistance to meet those needs.

*"If parents are not capable of providing necessary care for the child, the health care workers/teacher have an obligation to follow up and ensure the child get what it needs. The Individual Plan for the patient should include follow-up/oversee treatment." (Norway)*

*"Assessment of the family's capacity is done by the Family Physician upon first contact with the family. In case of parenting problems or if the family is living on breadline and there is a lack of financial means, the family nurse can visit the child at home, ask for help from the social worker, child protection specialist or refer the child to a paediatrician." (Estonia)*

Countries that do not perform parental assessments have endorsed bringing in legislation to assess parents' abilities and needs when caring for a child with ADHD (e.g. Iceland). In some countries, an assessment is performed only in cases of suspected violence or neglect.

##### **Parents' associations and NGOs**

Families may also be supported by voluntary organisations, which in some countries are widely available and comprehensive.

*"ADD-ADHD Cyprus is a voluntary organization. They offer lectures, seminars, support groups, guidance/coaching, special education lessons, occupational therapy, speech & language therapy, assessments and advocacy." (Cyprus)*

Although a wide range of services are provided, many tend to focus on the emotional support, social networks and education of the parents to help them care for their children. These organisations are sometimes parent-led:

*"In general, parents' associations are doing a great job, especially regarding coaching and teaching the parents how to handle the problems they are experiencing with their child's ADHD. Courses for parents, networking, seminars, etc. are being offered. It is often the parents themselves who are responsible for coordinating these activities." (Denmark)*

In the Czech Republic, one support group in particular provides a range of supports and is involved in care coordination.

*"Club [NGO] activities take place at several levels and include educational workshops and lectures for parents and educators, group work of parents and children, basic social counselling and rehabilitative exercises and consultations. The club is also the venue for coordination of comprehensive care for children with ADHD." (Czech Republic)*

##### **Social care**

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Professional psychosocial support for parents, guardians or siblings of a child with ADHD is available in most countries, with the referral made by the primary care physician or a specialised professional involved in the child with ADHD's care. In some cases, counselling or other psychological support for family members will be incorporated into the care of the child with ADHD:

*“Part of the services offered by Mental Health Centres, ‘Centres for Diagnosis, Differential Diagnosis and Support’, the ‘Home-based provision of Nursing and Specialised education services’ and NGOs/Associations..., include the provision of professional counselling/psychological services to the family members of the child with ADHD.” (UK)*

However, in other countries, the family members would have to seek psychological support independently and bear the costs:

*“Parents and siblings have to visit self-help groups or advisory offices autonomously. The attending doctor might provide relevant contacts to the family.” (Germany)*

### **Respite care**

Respite care for children with ADHD exists in most countries, most commonly provided by the local government or voluntary organisations, but may be fee-based or difficult to access for ADHD.

*“The request must be sent to the care insurance or youth welfare office/social welfare office. If integration assistance is not approved, parents have to [avail of] respite care without support from the state.” (Germany)*

This might be related to the perception that respite care is rarely utilised by children with ADHD or is not necessary for families of children with ADHD:

*“These services would only be available for children who have serious problems, usually more diagnosis than just ADHD.” (Iceland)*

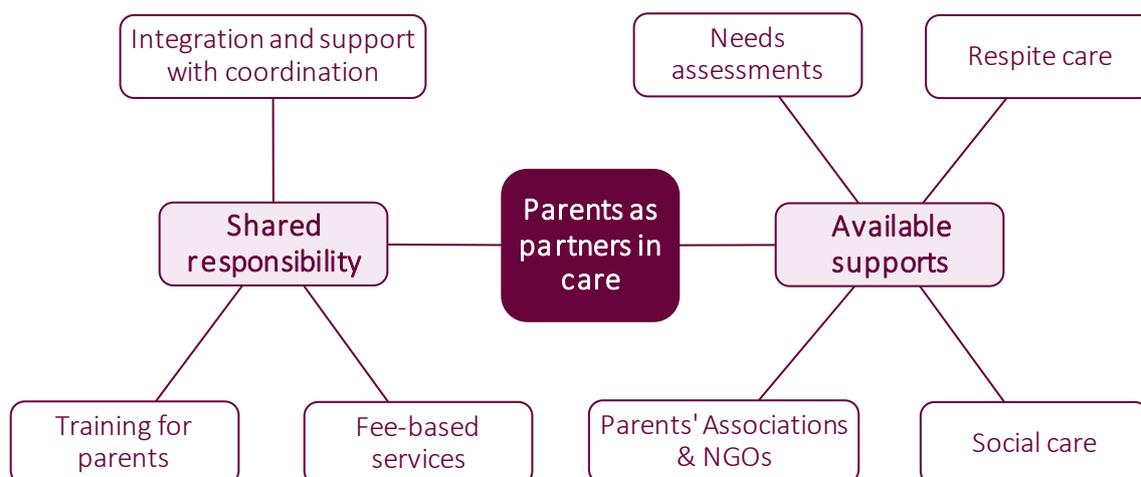


Figure 4.431: Emergence of Global Theme “Parents as partners in care”

### 4.3.3. Care coordination

The Global Theme “Care coordination” describes the importance of aspects of care related to care coordination, promoting individualised, team-based care that engages with community-based services and is defined by legal structures. These four key elements represent Organising Themes.

#### 4.3.3.1. Individualised care

##### **Written personalised care plan**

A number of the countries reported that policies to provide a written personalised care plan for children with ADHD are in place, for example:

*“There are national standards and guidelines which indicate that all service users of mental health services should have an individualised care plan: ‘Each service user has an individual care and treatment plan that describes the levels of support and treatment required in line with his/her needs and is co-ordinated by a designated member of the multi-disciplinary team, i.e. a key-worker.’” (Ireland)*

These plans may focus on the experiences of each child and providing for their needs over and above their diagnosis, and may utilise a holistic appraisal of the child’s needs and flexibility in the delivery of care:

*“The examination (on which the personalised plan is based) applies a holistic approach, for example, it includes: development and behaviour, family relationships, school, health, leisure time activities and friendships, and other relevant factors... The course descriptions/course of treatment in psychiatry for*

*children with ADHD is individually tailored within the framework of the package. If the child needs more help than the fixed defined times, there is a possibility for this. It is flexible. The planning of the elements of the package course is based on a medical assessment of the patient's needs as well as wishes." (Denmark)*

Despite the importance of having an individualised care plan, some countries do not have policies or guidelines to ensure this takes place. This relies on the willingness of the individual care provider to make a personalised plan of care:

*"Each practitioner makes a plan of care on his own way. There are no mandatory guidelines/procedures which must be adhered to. There is also no policy that practitioners have to make a written personalized plan of care. Especially for pharmaceutical therapy an individual treatment plan including the achievable goals should be made." (Germany)*

However, it appears that such care plans are often made despite the lack of regulations, but the quality, scope and effectiveness of the plans may be inconsistent and insufficient.

*"There are no written procedures, but the form of plan of care is dependent on the primary paediatrician and other professionals involved in care (e.g. team members of the group practice). There is no information on the care plan use, quality and evaluation, but there are indications that the care plan is commonly being made." (Croatia)*

### **Specific care coordinator**

In many cases, there is a specific professional appointed to coordinate care for each child with ADHD, helping to actualise the personalised plan, if such a plan has been made. This coordinator may be a GP, paediatrician, psychiatrist, psychologist, social worker, or caseworker in the municipality and there are varying levels of regulation surrounding this. In some countries, the coordinator has legal responsibility:

*"The caseworker could have the coordinating role (between hospital and community services). They have a legal obligation to bring together the threads of the individual child and family." (Denmark)*

In others, there are recommendations:

*"The recommendations of the HAS recognize the need for a coordinator, at best the general practitioner, responsible for initial orientation, coordination of care, and follow-up." (France)*

In others, the coordination is left to the discretion of the care professional:

*"Level of coordination is fully in the hands of the child and adolescent psychiatrist who is the registering doctor for a person diagnosed with ADHD." (Czech Republic)*

### **4.3.3.2. Team-based care**

#### **Multidisciplinary teams**

The need for multidisciplinary teams is widely recognised and many countries use teams composed of mental health clinicians, primary health physicians and social care professionals. This facilitates coordination between primary and secondary healthcare and social care, and multidisciplinary teams often go hand in hand with having a specific coordinator assigned to the child:

*“The first specialist is the Family Physician/Nurse, who collaborates with the family and other specialists needed for child. The healthcare providers’ team includes the following specialists: a psychiatrist, a psychologist, a physiotherapist, an occupational therapist, a speech therapist, a child protection specialist and a social worker. Health care and social services work in partnership.” (Estonia)*

The NICE guidelines from the UK recommend that multidisciplinary specialist ADHD teams and clinics are formed, ensuring that “clear lines of communication between primary and secondary care are maintained.” In Denmark, multidisciplinary “network meetings” are held to agree on the roles and responsibilities within the team and communicate these with the parents:

*“In the diagnosis of the child in child and adolescent psychiatry, network meetings will be held where both parents, school teachers, social workers, care workers and other relevant stakeholders are invited. The primary aim of these meetings are to provide parents with an overview of the parties involved, and how each of them can contribute to support the child. ... The network meetings ... clarify the roles, e.g. who is responsible now, and for what, who is the coordinator on the case, who is in charge of summoning parents to the different actions, etc.” (Denmark)*

A Portuguese project providing care for children with complex mental health needs utilises multidisciplinary teams responsible for care coordination:

*“One of the best examples of good practices in the field of children's mental health is a project of the Algarve Regional Health Administration, called Support Group to the Children Mental Health (SGCMH). ... These programmes, that cover the whole Algarve region, are carried out through close monitoring, favouring home visits, focussed on the development of parental and family responsibilities. This protocol fulfilled the lack of child and adolescent psychiatric services or specialized units in the hospital units of the Algarve, allowing the creation of first line multidisciplinary teams, supervised by a consultant of childhood and adolescence psychiatry.*

*The groups or centres have the following functions: screening, assessment and care of less serious cases (children/families at risk or with mild psychopathology); coordination and partnership with other community structures (e.g. social services, schools and preschools, protection committees of child and youth at risk, early intervention teams, host institutions for children at risk, projects of local psychosocial intervention, care centres for drug addicts). The most complex situations are referred to the Hospital Dona Estefania.” (Portugal)*

As with some localities in this Portuguese project, some countries mention care centres (to a varying degree of specialisation) where children with ADHD can receive the majority of the care they need in a single location.

### ***Continuity of team***

Some countries ensure continuity of the team providing care to children with ADHD through policies or procedures stating that they must be seen by the same team each time or must have a specific named physician, e.g. Croatia, Finland and Spain. However, a number of countries also reported that continuity of care team occurs on the basis of a geographical catchment area alone, e.g. Ireland. Indeed, children with ADHD may see the same team because appropriate specialists operate in only a small number of places:

*“Unless the family is moving from one locality to another. Estonia only has 2 children’s hospitals and the likelihood to be treated by the same healthcare provider is very high.” (Estonia)*

As with some other issues for best practice, even without policies and procedures clinicians and parents prefer and seek to have the child cared for by the same team over time:

*“There are no procedures which ensure that children with ADHD are treated by the same healthcare specialist every time, however in practice it happens. A specialist doctor who is taking care of a child may be chosen by the parents. They can influence the continuity by their personal choices – if possible.” (Poland)*

Again, this depends on the inclination and efforts of individuals and the specific contexts of each case, rather than being guaranteed to every child.

### ***Insights from DIPEX: Continuity of team***

Seeing the same GP each time was described as important, as a long, trusting relationship with the GP aided an understanding of the child’s medical history and the family situation, leading to a broader approach to providing support. Participants disliked repeatedly explaining their or their child’s health condition to different clinicians and valued feeling understood, remembered and familiar with the doctor, particularly with respect to mental health issues. Participants in the Netherlands were less concerned with this type of continuity. Almost all participants reported that they saw different professionals each time they went to the doctor.

*“This doctor is always the same?”*

*No, they change, they change*

*Yes and how do you feel about it?*

*I don’t like it*

*Why?*

*Well, because each time my mother has to explain everything again... and they have changed many times” (ID58,S,M,Child)*

### **4.3.3.3. Engagement with community-based care**

A number of respondents indicated that community-based services are a key component of care in their countries. Community-based care may be coordinated by the primary paediatrician

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(Croatia), the GP (Norway), the family assistant (Poland) or for example, in Portugal, “no one in particular”, as it depends on each hospital.

### **Engagement with social care**

In some countries, social care is embedded within institutions and social workers provide a central role in coordinating care for children with ADHD:

*“There are social workers in all local government structures and in hospitals. The social worker is a case manager for children with ADHD in carrying out the activities according to the rehabilitation plan in time ... Health care and social services work in partnership.” (Estonia)*

In other countries, a range of social care services might be available in various community-based organisations (see Figure 4.44), but are not explicitly coordinated. For example, in Latvia, links between healthcare and social care are made by the GP:

*“Social care is municipality based. Usually the GP has contact with the social worker. All social assistance family can receive in place of living.” (Latvia)*

### **Role of municipalities**

In some countries, a large share of responsibility for the child, most commonly for social supports or other ongoing non-clinical care, lies with the municipalities:

*“Once a diagnosis is made and medical treatment is decided on, the responsibility for educational or social support lies in the municipalities.” (Denmark)*

In Finland and Norway, for example, a case worker is appointed within the municipality who is responsible for arranging a variety of elements of the child’s care:

*“There is a person who is in charge of individual care and rehabilitation plan (at municipality).” (Finland)*

### **Role of the school**

Respondents from several countries reported that the school plays a central role in diagnosis, ongoing monitoring and care, as well as educating the child appropriately for their needs. For this reason, engagement between the healthcare providers, parents and school is useful. The Estonian respondent, for example, indicated that the main social care available to children with ADHD in the community is provided by psycho-pedagogical professionals in the school.

In Iceland, the school has responsibility for delivering the child’s care:

*“When comorbid disorders or other additional difficulties are diagnosed, the relevant care recommendations and referrals are made, written in the child’s assessment report and delivered to the parent, the school and school psychological services in a special meeting. At this meeting the school authorities formally take on*

#### **Social care providers included in responses:**

- social worker
- child protection specialist
- special educator
- social pedagogues
- family assistant
- parent groups
- youth welfare office
- self-help group

*Figure 4.44 List of care providers referred to by respondents*

*the responsibility of carrying out the recommended care for the child and follow-up. If further assessments are needed at a later time, it is the school's responsibility to refer the child back to the assessment facilities." (Iceland)*

In many countries, the school is involved in providing community-based care and as such, effective care may benefit from engagement with the school.

#### ***Insights from DIPEX: Role of the school***

Parents and children expressed that the role of the school was an important issue to them. Many parents of children with ADHD were disappointed and experienced a lack of understanding of ADHD-related behaviour among staff in mainstream schools. In Germany, parents reported insensitive comments directed at their child and severe effects on the child's mental health, even moving their child to another school. There was significant variation between participants' experiences, however, as some reported extremely helpful and understanding teachers. In some schools, the child was provided with an assistant, which was generally considered to have a positive impact on the child's concentration and school performance. Three participants attended a special school for children with ADHD and remarked on the benefits, which included smaller class sizes, teachers with specific training, a less strict ethos and mental health specialists available on site. Participants believed that more special teacher training regarding ADHD, as well as mental health more generally, would improve their children's experience of school.

The findings from the meso-level research emphasised the coordination and communication between community-based care and specialists, while from the patient perspective, the experience and day to day role of the school was a priority.

*"We spend about 180 hours in finding the right school. Those 180 hours were too few in my opinion, because we did not manage to talk with the all the staff. We should have had done it, because it is very important that they can have a good relationship with everybody." (G, F, parent)*

#### **4.3.3.4. Legislation and guidelines**

##### ***Cross-sectoral legislation***

A need for horizontal coordination (between sectors), as well as vertical coordination (between primary and specialist healthcare), has been recognised:

*"Apart from the multidisciplinary team needed to take care for these children, there is also a need for a better coordination between voluntary organizations, the State, health care providers and community based services." (Cyprus)*

However, many countries reported that there were no policies or procedures to ensure such care coordination. For example, Denmark indicated that policies promoting care coordination only apply within sectors rather than between sectors. Iceland reported a lack of policies regulating the roles of primary and specialist services:

*"At ministerial level there is a lack of an official policy regarding the services for children with ADHD and their families. There is no law that states that such services*

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*should exist, and there is no policy on the division of services into 1., 2. and 3. line. In praxis the different service centres themselves decide what serviced they provide and for who. Thus this can be changed unilaterally.” (Iceland)*

### **National policies**

In the UK, there are policies regarding integrated care, but detailed plans and procedures tend to be set by individual Trusts and Health Boards running the services based on general national standards. Several other countries do not have national policies regarding care of children with ADHD but instead have regional guidelines. This may be due in particular to autonomy of regional authorities (e.g. Germany, Sweden).

*“Currently, there are large regional differences. Each state/(sometimes) each institute uses their own procedures in their regional networks.” (Germany)*

This may result in inconsistencies in the care of children with ADHD depending on the location.

### **Transition to adult care**

In addition, there is often insufficient regulation and guidance regarding the transition to adult services. Countries such as Croatia, Greece, Iceland and Latvia, referred to a lack of procedures managing transitions as a barrier to accessing appropriate adult care, while others reported that the strict delineation between child and adult services hindered transition.

*“Management and administrative bureaucratic procedures as barriers, e.g. adolescents with ADHD are automatically referred to adult care services at 18 years of age with a negative impact on a quality transitioning to adult care.” (Spain)*

Flexibility around this occurs in Finland, where adolescent psychiatry can be accessed until the age of approximately 23 if required. Countries with policies regarding transition to adult care include continuity of care and coordination via a key worker, for example:

*“Policies and procedures mention continuity and similar procedures for children and young people, for example the existence of a case manager, preparation for career, access to care and assistance. Plans are the same for children and adults with ADHD, and expressly mention the continuity of care.” (Romania)*

Other places are continuing to improve their policies; in Finland, for example, the next current care guideline will incorporate the whole life course.

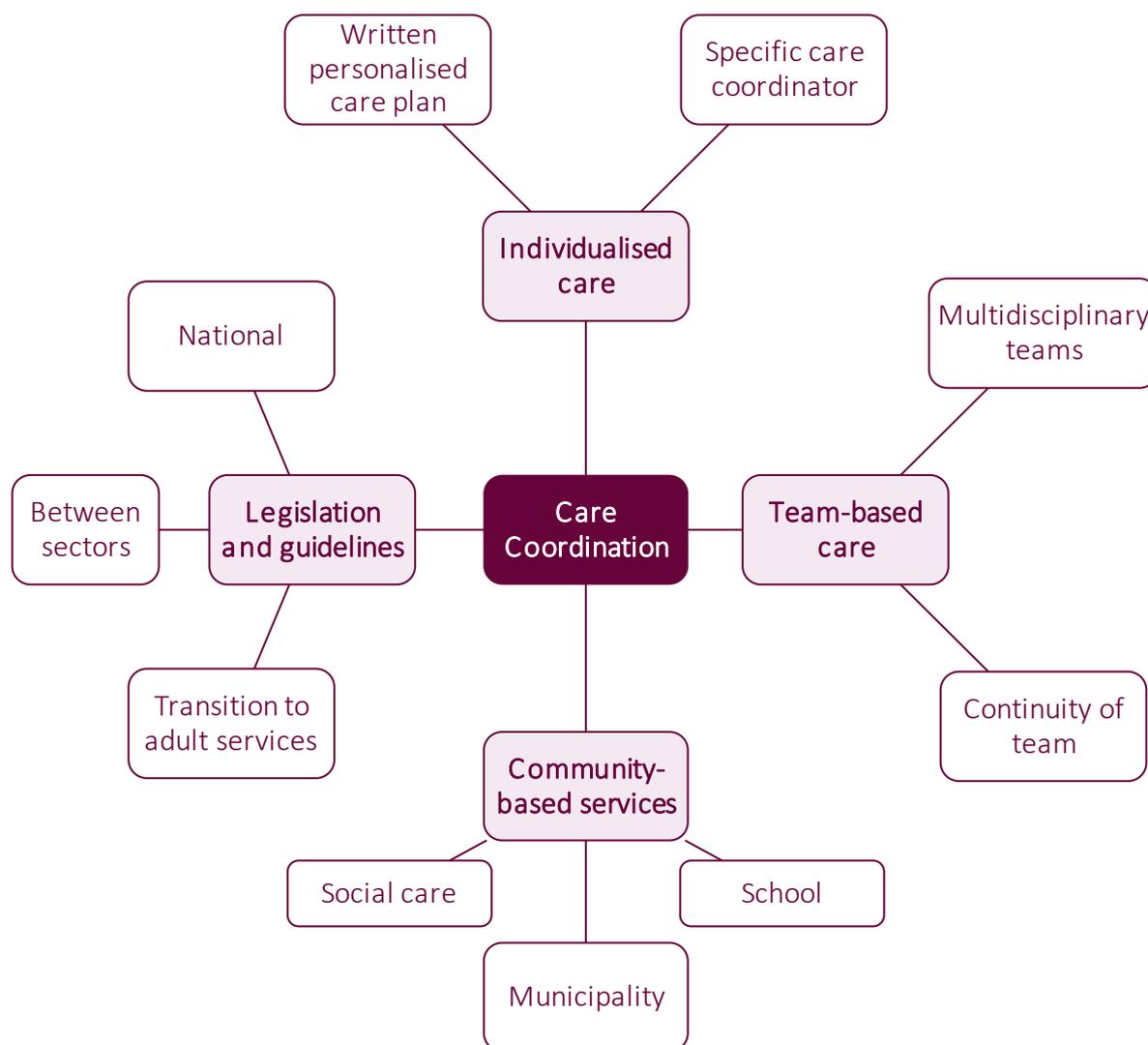


Figure 4.45: Emergence of Global Theme “Care coordination”

#### 4.3.4. Facilitators of optimum integration of care at the interface of primary and secondary care for a child with ADHD

A thematic analysis of Country Agents suggests that the following are the main facilitators of integrated care:

- Parents are integrated into care as partners with shared responsibility with professionals
- Supports are available for the family
- Access to secondary care for ADHD and comorbidities should be accessed via primary care
- The availability of paediatric and adult specialists and expertise
- Adequately resourced services
- Individualised care plans which are managed by a specific care coordinator
- Care is provided by the same multidisciplinary team
- Involvement of social care, school and municipality in care is deemed important

- National legislation needs to be developed to coordinate between sectors

#### 4.4. Survey of Change in the care of children with ADHD

Respondents were asked to evaluate the overall integration of care for children with ADHD and to identify relevant socio-cultural factors, such as key facilitators and barriers, public awareness and political engagement, in the last five years.

##### 4.4.1. Overall integration of care for children with ADHD during the last five years

The *Survey of Change* section of the questionnaire invited each country agent to provide a commentary on how they evaluated their country's progress with regard to meeting the integrated care needs of children with ADHD. As illustrated in Figure 4.46, just over half of the Country Agents felt that in the previous 5 years the integration of care for children with ADHD had improved within their national context, whereas almost half had suggested that it had stayed very much the same. The remaining two countries reported that the situation in their country had declined and one country did not respond.

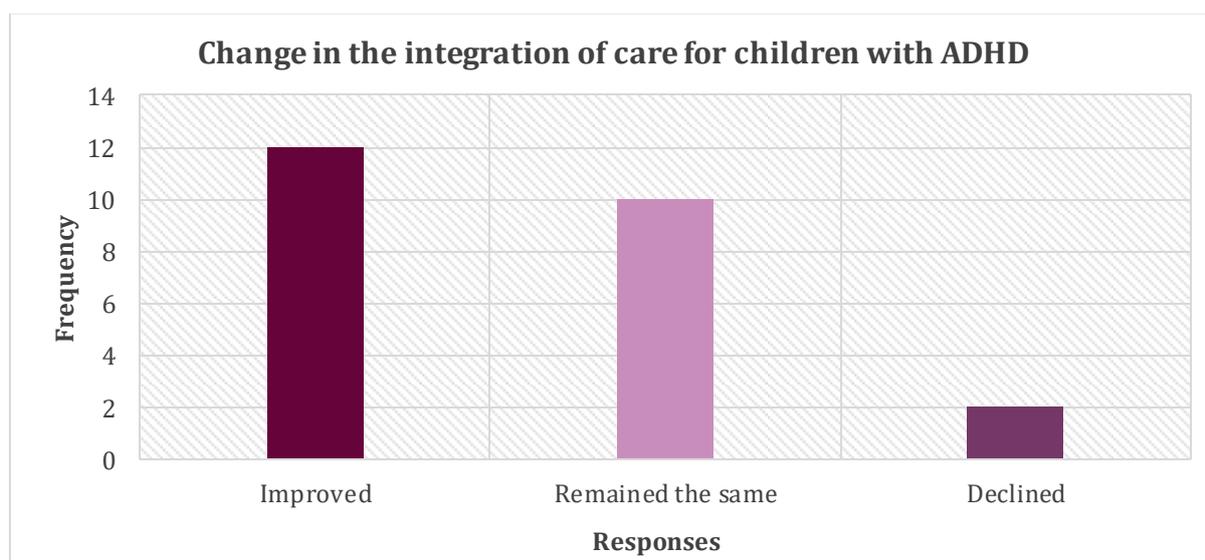


Figure 4.46: Change in the integration of care for children with ADHD

The concepts of improvement, stasis or deterioration were measured based on a particular collection of variables which included public awareness strategies, wider EU involvement and improved funding and resources. It was anticipated that these concepts would provide useful markers to gauge the overall trajectory of the integration of service provision and service delivery within each country. The feedback from each of the country agents indicated that there was a dichotomy across the different countries with regard to service integration. Analysis of the feedback suggested that the countries that experienced improvements in funding and policy development were also the same countries who reported improved public awareness and professional relationships. It was also evident that there were similar incidences of improvement and stasis when the integration of care for children with ADHD, with the number of countries experiencing positive change being similar to those countries who did not report

any positive changes in their integrated care approaches. These similar numbers are illustrated in Figure 4.47, Figure 4.48, Figure 4.47, and Figure 4.48.

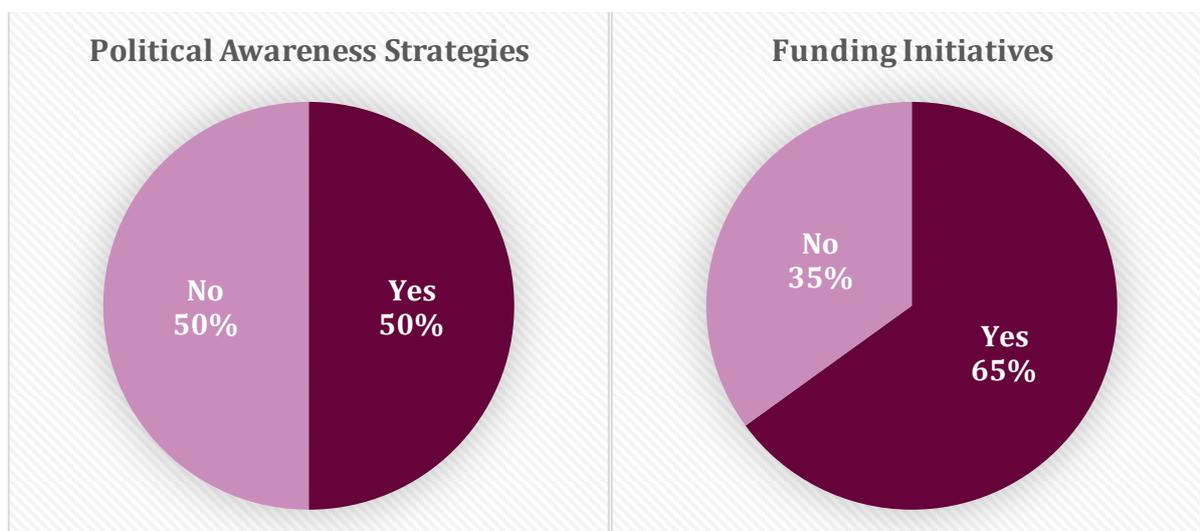


Figure 4.47: Political awareness strategies reported      Figure 4.48: Funding initiatives mentioned

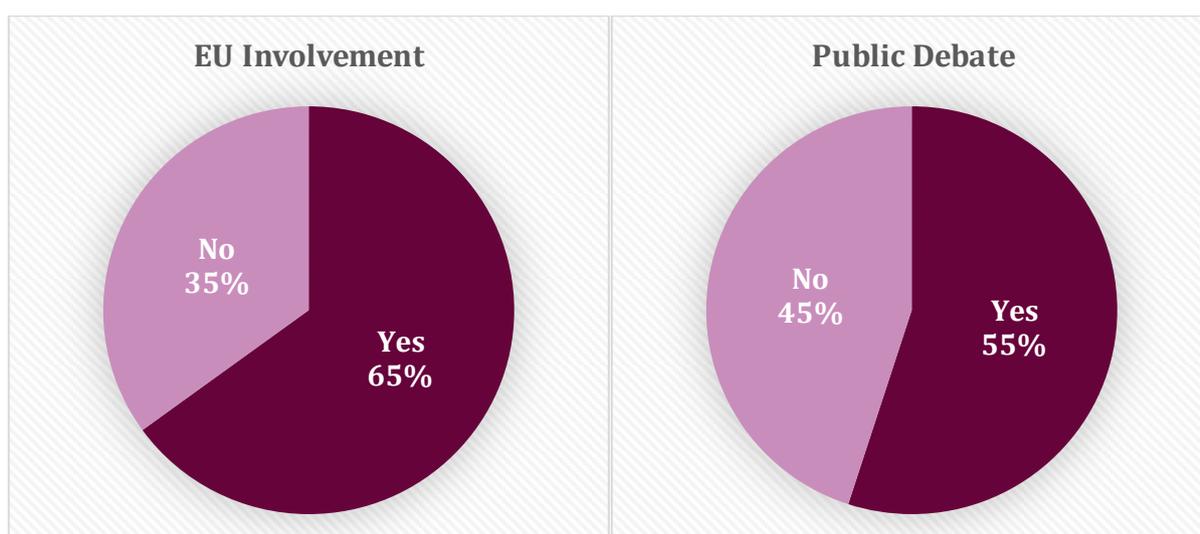


Figure 4.47: EU involvement reported      Figure 4.48: Public debate mentioned

#### 4.4.2. Main barriers and opportunities

Analysis of the feedback provided in the Survey for Change identified a number of key core themes that seemed to contribute positively to improvements in integrated care and service delivery for children with ADHD. These core themes included Professional Relationships, Public Awareness and Advocacy and Policies and Standards. These appeared to be the pillars that robust and comprehensive integrated care systems were built upon. These themes were evident both in the reports of countries who had established these improvements and in the reports of those who were still endeavouring to develop these initiatives.

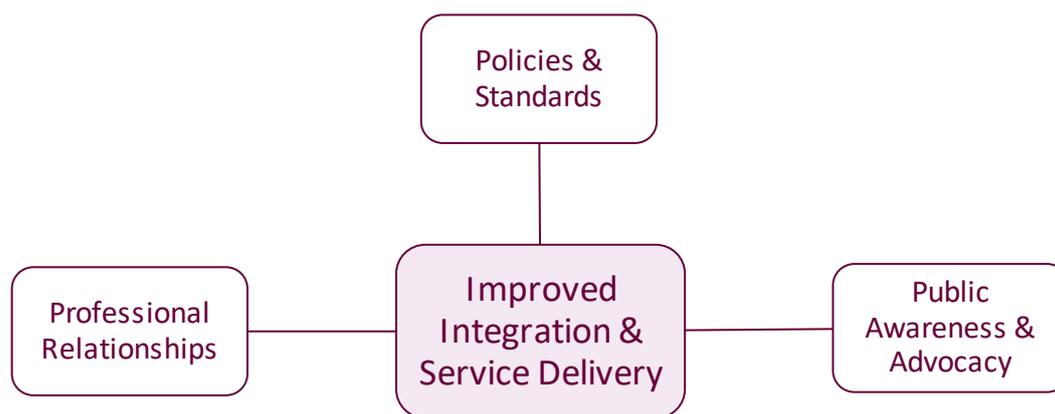


Figure 4.49: Thematic network emerging from the Survey of Change in the integration of care for children with ADHD

### 4.4.3. Professional Relationships

A number of country agents reported that there was a need for greater awareness of ADHD within groups of professionals who were involved in the care of these children. It was felt that this would lead to more timely diagnosis and the initiation of treatment plans. There was also a common plea for ADHD in childhood to achieve more attention in the public discourse. Some representatives reported the benefits of having functioning support groups in the community for parents of children with ADHD, and the development of a ‘family assistant’ which provided practical care to children with ADHD.

Some countries reported that familiarity with the medical and educational treatment approaches for children with ADHD had improved and this had developed their ability to deliver integrated services. Although information and training with regard to ADHD treatment was deemed positive, some countries suggested that this was being provided by the pharmaceutical industry as opposed to expert staff within their public health education system.

Some country agents suggested that for some health and education professionals, ADHD is not recognised as a neurodevelopmental disorder which, it was suggested, can lead to fragmentation of clinical and diagnostic categories to the detriment of generalist structures.

Most country representatives were unanimous when they discussed the need for collaboration agreements between NGOs, social care centres and health care providers and how this needed to be a core component to Family, Youth and Social Policy. In general there was a consensus that the integration of services needs to focus on the importance of cooperation across sectors with regard to the implementation of various action plans and guidelines which in turn will lead to the development of care pathways across sectors.

However the establishment of pro-forma clinical care pathways may not be that straight forward. The analysis of the commentary in the Survey of Change captured many diverse views as to what the core clinical approaches to ADHD must be, depending on what particular philosophical background was favoured. Some services endorsed the establishment of special education services in public schools where it was recommended that school psychologists should be employed to screen children who are suspected to be suffering with ADHD. This was

proposed as there was an impression that there is an epidemic of under-diagnosis of ADHD by primary care physicians and education specialists, which can lead to late diagnosis, late treatment and poorer prognosis.

However other country agents suggested quite the opposite. These country agents proposed that in their experience there were examples where there was an over-medicalization of children with behaviour problems who are labelled with an ADHD diagnosis. These country agents suggested that more attention needs to be given to the concept of differential diagnosis and comorbidity as opposed to supporting a singular ADHD diagnosis. These services would adjudge service improvement to be visible when there is an observable decrease in the prescriptions of medicines for ADHD.

These diverse views might explain why there are difficulties in establishing clear clinical guidelines when it comes to ADHD care pathways. The question of adhering to specific clinical guidelines can be difficult in the presence of a divided ethos in policy makers.

Other themes concerning professional relationships suggested that split competencies exist in differing sectors like health and education. It was suggested that this inhibits the integrated delivery of complex care when it comes to ADHD. Many agents reported an absence of appropriate multi-disciplinary coordinated team for the care of children with ADHD and a dearth of staff with specific education and expertise when it comes to identifying and treating ADHD in children. There were also concerns raised that a knowledge deficit with regard to ADHD may exist amongst primary care providers who are generally the first contact providers, which can delay diagnosis and treatment

In summary, although some services report slow improvements in the delivery of integrated care for children with ADHD, there still is a lack of trained professionals: psychologists, social workers, special educators and general educators in the area of ADHD. Many country agents reported a lack of real involvement of educational services in organizing individually tailored education plans for children with ADHD which they accounted to be as a result of insufficient training and the lack of specialized professionals, such as doctors, psychologists, educators, social workers, occupational therapists.

#### ***Insights from DIPEX: Attitudes of GPs to ADHD***

The attitudes of GPs towards ADHD varied in different countries. Parents in Germany were the most negative about GPs' attitudes, reporting that they are dismissive and do not consider ADHD a "real" condition. As a result, some parents in Germany felt ashamed and did not want to see doctors about their child's problems.

Participants valued when healthcare professionals showed an interest in their lives and how they manage their condition, especially when they communicate directly with the child and treated them as "normal". Some parents described examples of doctors talking clearly with their child and taking their ADHD into account. Some children with ADHD talked about seeing a psychiatrist or psychologist and valued that relationship and opportunity to talk about their experiences.

*"I am really satisfied, she asks even about things she doesn't need to, she knows how to communicate with my son, right. She just knows: [son's name], sit down. Now we are going to do that and that', she explains everything to him. 'Now we are going to listen.' That's what I like about her. She knows that my son is quite wild, so she gives him a toy and things like that. (...) She knows how to communicate with him, what to do with him, with children." (ID37, CZ, F, parent)*

#### 4.4.4. Policy and Standards

A recurrent theme in the analysis of the Survey of Change was the lack of specific coverage of ADHD within national health policies and the absence of protocols regarding diagnosis and management of children with ADHD. There were a number of explanations for this deficit which included a lack of interest at a ministerial level and/or a lack of political will. However given the diversity in approaches to the assessment and treatment of ADHD, which was evident in the feedback from the various country agents, it is not surprising why explicit and clear procedures, which would effectively regulate integration of care for children with ADHD, could be problematic to establish and publish.

There were also a number of comments that suggested that there were no educational policies for professionals with regard to ADHD issues, which left teachers, social workers, therapists, medical doctors and psychologists without any degree of clarity in terms of their role in the diagnosis and treatment of ADHD.

The conceptual difficulties were well captured by one country agent who remarked that the reasons for the delay in the implementation of coherent universal policies include; a biased education and training curricula, a lack of coordination between professional disciplines and an absence of clear definitions of what the individual and collective responsibilities are regarding each profession and service who are involved in the care of children with ADHD.

However, some countries had attempted to establish a clinical pathway to guide primary care physicians in cases where Attention Deficit and/or Hyperactivity Disorders were suspected. These were published in order to assure that uniform procedures were available, particularly to Primary Care doctors who were tasked with early diagnosis, treatment and follow-up. However, it was noted that all of the published clinical recommendations on the diagnosis and treatment of ADHD were reported to originate from the discipline of Psychiatry, which some challenged as a one-dimensional approach to treatment. Some commentators advocated for a review of the published guidelines in order to include the views of other professionals who may have different professional approaches. Many of the country agents claimed that improved cooperation with other professionals would lead to better therapeutic options and improvements from practitioners.

It is also suggested that some health authorities collect data in order to establish how many children will need a variety of different services in the treatment of their ADHD. This data is then used to devise clear policies which outline what a comprehensive service should include, and what institutions/centres should be involved. The data should also be used to guide what authorities should be responsible for co-ordinating different aspects of care. The core issues regarding the accountability and responsibility of varying professionals appears to pose

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challenges to the establishment of clear coherent protocols and guidelines in the integrated treatment of ADHD.

It was unanimous from all of the country agents who noted improvements in service delivery that more emphasis on coordinated and integrated intervention was, and is, most effective.

One such commentary described how their national policy aimed to develop a more integrated approach to the generic needs of the children and their families. In order to initiate an improvement of services, contractual arrangements with providers was amongst the top priorities for specialist therapeutic services and education. This feedback suggested that health care professionals need to demonstrate a willingness to participate in fruitful dialogue in order to arrive at mutually beneficial contract terms which has the child and family at heart.

#### **4.4.5. Public Awareness & Advocacy**

Some of the feedback in the Survey of Change suggested that there was an overall low level of parental education and/or awareness of ADHD within European child health systems. Some even went as far as to claim that there were examples of misinformation about ADHD and suggested that this resulted in a lack of social recognition. Some feedback suggested that the weak knowledge of primary caregivers was cause for concern, as they feared that this may lead to a delay in diagnosis and the commencement of therapy which risks an accumulation of psychosocial problems during this period.

There was an observable view that the lack of public awareness of ADHD was also evident in a wider social context which involved a lack of public tolerance of people and children with a whole range of disabilities.

Some country agents reported how some parents of children with ADHD were working together with non-profit organizations to advocate for wider policy changes. Others reported that parents' associations' who cooperated with mental health care professionals were also advocates for children with ADHD in the community. The predominant role of parents' associations appeared to be to improve the rationalization of care within care systems.

Some of the more positive feedback reported that general public's knowledge of ADHD was increasing, and they suggested that this knowledge led parents to not feel as ashamed or guilty because of the child's disorder. The overall sentiment of the feedback suggests that caring for a child with ADHD is difficult and that parents need many extra supports to assist them to manage. One country agent reported that their findings suggested that 'most of the parents of ADHD children were divorced, which even makes the burden of the situation heavier'.

There was unanimous agreement the there is a need for more parents' associations, combined with the interest of other services like schools. The feedback suggested that in order to improve their advocacy role, services needed to involve parents' associations in the care process improvement.

Much of the public awareness discussions and debate in the media were reported to be about the inclusion of children with ADHD in mainstream schools and whether special schools or specific classes are required.

Other mainstream media discussions surrounded the use of medication in the treatment of ADHD, and whether there are incidences of over-diagnosing children with ADHD. Other public discussions concerned the division of responsibility for the management of children with ADHD between the primary and secondary sectors. Some country agents reported that there were some coverage of ADHD in television, radio, newspapers which concerned the activities of associations and unions of parents who were raising generic public awareness of mental illness, and supporting modern intervention methods such as music therapy, art and creative therapies, group therapies etc. The problem of unequal access to care was also discussed on occasion.

Other public discussions concerned undiagnosed adults with ADHD and their difficulties accessing care or medication.

In terms of advocacy, an online petition was started in one of the representative countries which asked for support for ADHD services from the government, but only 300 supporters signed the document on the internet. Another country agent described how they were planning to organize peaceful demonstration to raise awareness this April.

In summary, it appears that ADHD has been a controversial theme in many countries for many years, within the child health professions and the public. The rate of prescribed ADHD medication has increased in a linear fashion and this has caused much debate. These discussions about the increased rate of medication has often been linked to the debate about an “educational crisis” with lack of structure in schools and other support services.

#### **4.4.6. Service Delivery Improvement**

Some of the feedback outlined how new school reforms have resulted in changes that may be challenging for children with ADHD, e.g. numerically larger classes, longer school days and a greater focus on inclusion in schools. Because of these school reforms, teachers reported having less time to meet with psychological counsellors and have less time to care for children with special needs. Also, these reforms have led to fewer services being offered to children with special needs such as children with ADHD.

Many country agents reported that not every child with ADHD has an education assistant and the long distances between the place of dwelling of the families and the persons in charge of their individual care and rehabilitation make co-ordination meetings difficult. Some countries reported that decentralised health care systems can cause access to care provision to be different in differing parts of the country. These regional variations make access to care services more problematic in some distal regions.

A consensus amongst much of the feedback suggested that a lack of interdisciplinary cooperation amongst service providers such as psychotherapists and other healthcare professionals can create challenges in their transition into adulthood; sometimes causing long waiting times.

With regards to specialist training, some country agents reported that some multi-professional teams are available in primary and secondary health care, and the members of these teams can be observed to participate in relevant further education.

There was a consensus amongst a lot of the feedback that to improve the access and co-ordination of services, future health care reform will need to integrate social and health care, and primary and secondary health care tiers. It was also suggested that there should be a national policy to develop and implement a national Electronic Records which will support the effective integration of care across a variety of services.

The feedback from a variety of representatives suggested that future service development plans should pay attention to the development of social support services for children with disabilities for planning and development, such as focusing on practical supports such as transport, employment, day-care and social home care. There were also recommendations to define clear clinical care pathways which include case coordinators with a nominated profile of their responsibilities.

There were some suggestions in the feedback that there are an increasing number of children who are being labelled with ADHD, many of whom are allegedly under treatment without having a confirmed diagnosis of ADHD from a clinical specialist.

Some feedback suggested that there was an increasing number of paediatric neurologists and paediatric psychiatrists the last number of years, who have become dedicated leaders in mental health care in regional hospitals. There were also accounts of new mental health nursing specialties with specific emphasis on ADHD.

Others reported that there are ADHD training programs which are offered in schools and day care centres which enable employees to prepare for the individual needs of the children and to provide more targeted support and it was felt that these programs strengthened the teamwork among different specialists. However, there was a consensus that there was a need to educate primary care physicians, paediatricians and social care workers about ADHD and possibilities of children with ADHD integration

Finally, funding was universal concern for many countries who discussed it in terms of creating barriers to service coordination. Some countries operate a refund policy where the state would refund parents for their children's treatment/therapies based on agreed pre-determined costs (set by the state) per treatment category. Parents would pay health providers and then be reimbursed by the state after submitting the necessary paperwork.

#### **4.4.7. Summary**

Overall the feedback is consistent with the message that there is a universal need for more coordinated care systems. These would be best created through improved specialist education for clinicians working with ADHD. There was also a consistent need for more public awareness and advocacy for children with ADHD.

The most striking aspect of the feedback was the notion that there are conflicting philosophies when it comes to the assessment and treatment of ADHD where the biological and social models fundamentally disagree on the theoretical underpinning of the diagnosis of ADHD and its treatment. Perhaps it is the clash in ideologies which fuel a resistance to implementing coherent service integration strategies because both sides disagree with the origins of its existence.

- Universal need for more coordinated care systems
- Need for improved specialist education for clinicians working with ADHD
- Call for more public awareness and advocacy
- Conflict between biological and social models of origins of ADHD may be a barrier to implementing coherent service integration strategies

#### **4.5. Synthesis of findings on the integration of care for children with ADHD**

The above findings were examined collectively and combined into a single model of factors that may contribute to integrated care for children with ADHD.

##### **4.5.1. Socio-cultural context**

The foundation for structures and processes required for care integration is the perceptions, attitudes and stances of professionals, parents, politicians and the general public. The perspectives of individual clinicians regarding the nature ADHD as a condition are influential in an arena mired in controversy, which threatens to hold back the progress of care for children with ADHD. There is a fundamental tension between those recognising a neurological basis for ADHD, others explaining symptoms as purely environmental and others who challenge its existence at all. Care of ADHD symptoms among children using a biological model, including pharmacological treatments, presents further conflict. This issue is a reflection of debates occurring within mental health fields in general, where the difficulty of selecting criteria and measuring symptoms can result in a wide range of possible courses of treatment, positioned in contrast to physical health conditions with tangible symptoms and simpler or more linear care pathways.

The stance of professionals is central in that their attitudes can influence perceptions about ADHD among the general public and in the political sphere. Developing public understanding of ADHD can lead to wider acceptance of ADHD, reducing stigma and empowering families as they seek help. Further, with advocacy and lobbying, the political will to prioritise mental health and invest in ADHD services may be increased. Thus, when all of these factors are in place, pressure to deliver effective ADHD services may be increased, resting on a wide base of support from professionals, parents, politicians and the general public.

##### **4.5.2. Policies and standards**

Two areas that could benefit from such support and contribute to more effective integration of ADHD care are written policies and standards and access to relevant specialists. Input from advocacy, professionals and policy-makers could lead to further regulation, recommendations and quality assurance procedures being put in place, which would provide standards to be met and the legal weight to follow them through. However, in order to accomplish this, consensus on the best approach must be reached, which is challenging when competing philosophies around ADHD itself exist. Policies and standards were reported to be more effective when formulated at a national level in order to provide consistently high-quality care across all regions. Care delivery would also benefit if the written structures encompassed the whole of the lifespan from infancy to childhood to adolescence to adulthood, as transitions between services present weak spots for continuity of care. The question is how to develop services and implement change when an underlying consensus among clinicians is lacking.

### **4.5.3. Access and availability to specialists**

The other key area relates to the accessibility and availability of appropriate specialists for the child with ADHD. This includes the existence of clinicians with suitable expertise and training within the health systems caring for children with ADHD and the ability to access these professionals when appropriate. Structures such as multi-disciplinary teams, stepped care or gatekeepers between primary and secondary care would contribute to integration of care by facilitating access to specialists. Specialist education for clinicians was highlighted as a particularly key area for improvement, involving further training on ADHD for primary care providers on the one hand, and increasing the number and expertise of mental health specialists on the other. A fundamental issue faced was securing sufficient resources to deliver effective services and particularly to ensure timely access to specialists.

### **4.5.4. Care coordination**

Both policies and standards and appropriate access and availability of specialists were cited as fundamental facilitators for effective care coordination, which should occur between primary and secondary healthcare, social care and schools. Coordination should aim to provide seamless care between and within agencies to ensure the individuals' needs are met in multiple spheres of life. Specific policies and standards that contribute to care coordination include a written personalised plan or formalised care pathway. Both provide a written overview of the care needed and steps to follow to assist in the care being sought. A designated care coordinator for each child was highlighted as extremely useful in managing the multiple aspects of the child's care and relieving some of the organisational burden on parents.

### **4.5.5. Role of parents**

Parents were described as playing a key role in the child's care in general, of course, but specifically with regards to care coordination, especially when other elements of the care interface were lacking. The provision of suitable resources for parents, including psychosocial supports and psychoeducational programmes, were highlighted as extremely beneficial for the wellbeing of the child and family as a whole. Strong communication between parents and the care coordinator, as well as other professionals, was also described as crucial, with parents being treated as partners in the child's care as an important goal.

### **4.5.6. Summary**

- Cross-sectoral coordination, including primary and secondary healthcare, social care and schools and the support and engagement of parents, is a facilitator of integrated care.
- Policies, standards and access to, and availability of, specialists were cited as the main facilitators of comprehensive care coordination.
- The wider societal context was influential with regards to applying pressure to fund and develop services, with public awareness, political will and parents' associations playing key roles.
- The attitudes of professionals regarding the theoretical underpinning of ADHD had wide-reaching effects.

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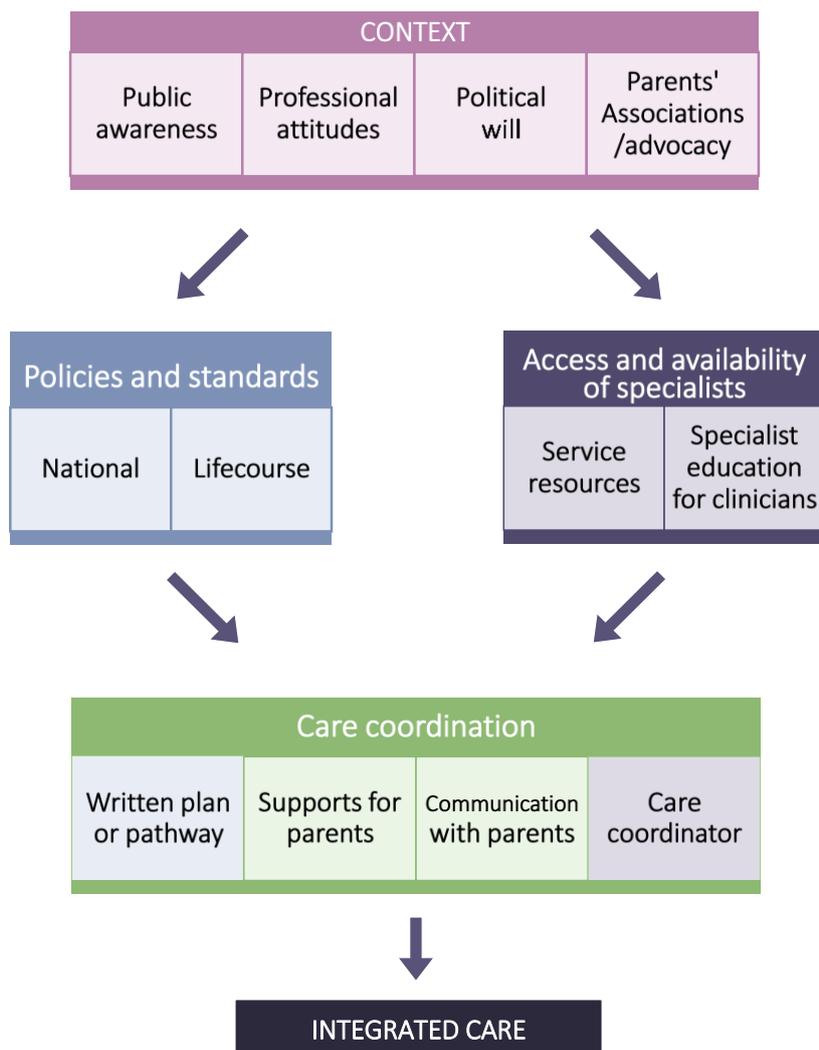


Figure 4.50: Synthesis of findings regarding the integration of care of children with ADHD

## 5. Methodological Approach and Limitations

This task analysed the current approach to managing the complex care needs of children with enduring mental health conditions at the primary/secondary interface in thirty European countries, drawing on expert perspectives and a survey of whether policies and procedures regulate specific aspects of care. The involvement of thirty countries across Europe was significant in itself and this task succeeded in keeping a wide focus, whilst also achieving the necessary depth to produce insight. The project drew on expertise from networks in child healthcare delivery, children's health research projects and knowledge from local agents working in child health settings and was informed by multiple disciplines including medicine, nursing, economics, informatics, sociology and policy management.

An advantage of the design of the main instrument used for this study is that it encompasses both the meso- and macro-levels of complex care for CAMHS. While the *Lucile-Packard Standards for Systems of Care for CYSHCN* were selected to focus on the meso-level organisation of services, the *European Survey of Change* provided a complementary elevated view of care for children with ASD and ADHD, with particular emphasis on public and political attitudes and awareness and overarching changes over the past five years. This can be seen in our discussion of the findings, where connections are made between meso-level factors and their wider context. The micro-level patient perspective was provided by the DIPEX work. Thus part of the uniqueness of this MOCHA work package is its focus on meso-level process and structures, complemented by insights into sociocultural facilitators of integrated care and patient and family experiences.

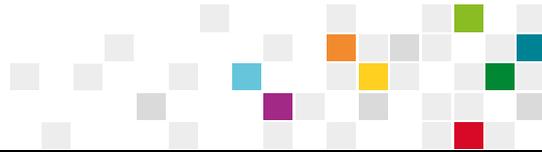
The ambitious scale of the MOCHA project necessitated an innovative data collection method, namely utilising remunerated Country Agents (CAs) to collect data on behalf of the MOCHA team. Key informant surveys are commonly used in social, political and anthropological research to obtain informed opinions (e.g. [35, 36]), and in this study, expert opinions. The mediated informant surveys completed with the aid of local Country Agents aimed to benefit from local insight, language proficiency and logistical ease.

However, while this decentralised approach proved efficient and able to reach into the healthcare systems of each country, there were also some limitations. The reliance on CAs over many rounds of data collection and Work Packages risked the fatigue of both CAs and their informants, despite remuneration of CAs by the MOCHA project. Some countries did not provide as much qualitative exposition as intended, which could be attributed to respondent fatigue, questionnaire design such as phrasing of questions or the applicability to specific healthcare systems, which may be in itself a finding. For example, if CAs struggled to locate appropriate experts to recruit, the selected experts were overworked or the questions asked did not target services in an appropriate way, this may explain missing data or minimal qualitative commentary received from some countries.

Secondly, the precise methods used by individuals CAs remain unclear, for example, the number and type of sources approached, the selection criteria used by the CAs when recruiting experts, whether face-to-face interviews were conducted or respondents filled in the questionnaires via email. Again, these factors may contribute to the richness of the data obtained, as countries where multiple local experts were consulted tended to produce more detailed descriptions of

the interface of care. Further, the type of professional interviewed may have influenced the type of response. Some countries sought information from primary, secondary and social care experts, while others may have consulted child psychiatrists exclusively, for example. In fact, there was a scarcity of data from social care experts in general the returned questionnaires. As well as types of professional, expert opinion may be grouped on an ideological basis, particularly in the case of ADHD and the controversy surrounding the nature of the condition and its pharmacological treatment (see Section 4.4).

Another feature of MOCHA is that it was conducted in English, and only individuals proficient in scientific English and their local languages were recruited as CAs. Translation was not included within the MOCHA methodology and these linguistic responsibilities were taken by the CAs.



Abbreviation	Description (using lay language)
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**SECTION B:**  
**Systems of care for children with complex mental health conditions in Australia (using ADHD and Autism as exemplars)**

**Ms Kate Paton and Professor Harriet Hiscock**

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A4	Autism Aspergers Advocacy Australia
ACP	American College of Psychiatrists
ADHD	Attention deficit/hyperactivity disorder
ASELCC	Autism Specific Early Learning and Care Centre
ATAPS	Access to Allied Psychological Services
CAMHS	Child and Adolescent Mental Health Service
CAPA	Choice and Partnership Approach
CRC	Cooperative Research Centre
DSM 5	Diagnostic and statistical manual of mental disorders 5
EU	European Union
FaCHSIA	Department of Families, Housing, Community Services and Indigenous Affairs
GP	General Practitioner
HCC	Health Care Cards
HCWA	Helping Children with Autism package
LADS	Learning and Attentional Disorders Society of WA
MBS	Medicare Benefits Scheme
MOCHA	Models of Child Health Appraised
NDIS	National Disability Insurance Service
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
NICE	The National Institute for Health and Care Excellence
PBS	Pharmaceutical Benefits Scheme
RACP	Royal Australasian College of Physicians
RANZCP	Royal Australian and New Zealand College of Psychiatrists
WP2	Work Package 2

## 6. Introduction

### 6.1. Brief background

Mental health problems account for a substantial burden of disease globally, with the World Health Organisation predicting that by 2030 mental health problems will be the highest ranking disease in terms of burden in affluent countries [37]. Much of adult mental health has its roots in childhood and adolescence, with up to 50% of mental health problems arising in this period persisting into adulthood [38]. Common mental health problems in children and youth include anxiety, attention deficit/hyperactivity disorder (ADHD) and depression, collectively affecting around 1 in 4 Australian children [39, 40]. These mental health problems typically require care involving a range of additional support services beyond the type and amount required by children generally, and need a high level of effective coordination between services. International research suggests that too often health services for complex needs are overlooked, disadvantaging a group of children with greatest need. This is likely true for Australia. However, we have a striking lack of data on the interface between primary care and secondary/tertiary care for children with complex mental health issues and the provision of continuity of care, quality of care and the level of family support in families of these children.

### 6.2. Models of Child Health Appraised (MOCHA)

The European Union (EU) Horizon 2020 project – “Models of Child Health Appraised (MOCHA) - A Study of Primary Healthcare in 30 European Countries” aims to compare and appraise existing national models of primary care for children, combining multi-disciplinary views and approaches to develop new, or improve on existing, approaches to prevention, early intervention and treatment, alongside integration into broader health services. Arranged in a series of nine work packages, MOCHA aims to examine the most effective model of provision of primary health care for children. In doing this, the project recognises the importance of childhood as early intervention and prevention to address the growing rise in adult avoidable chronic illness such as diabetes and depression. The project also aims to ensure equity in these future optimised models of care; making certain that complex needs and complex conditions such as mental health, are adequately supported by the same models. The MOCHA proposal addresses a research issue which has been overwhelmingly neglected, and results of the study should have international and long-standing impact.

In Australia, there are similar challenges to ensure that the health needs of children are adequately and equitably addressed. This document is arranged to create a companion report (from an Australian perspective) to questions posed through the EU Horizon 2020 project MOCHA in Work Package 2 – Safe and efficient interfaces of models of primary health care with secondary, social and complex care (WP2). Participation in this project is made possible through the National Health and Medical Research Council (NHMRC) European Union Collaborative Research Grant NO.1101321 which facilitates collaboration on EU Horizon 2020 grants.

This report will cover:

- the findings in relation to the MOCHA questions for ADHD;

- the findings in relation to the MOCHA questions for Autism; and
- key points of convergence and dissonance between ADHD and Autism findings.

### 6.3. Healthcare in Australia

Australia has a system of universal health cover – the Medicare Benefits scheme (MBS). Medicare is funded via a levy on taxable income, which is reduced or not applicable to low-income earners. Funding is distributed through the Commonwealth and State governments to provide primary, secondary and tertiary healthcare services. Medicare provides free or subsidised medical and hospital services including all primary healthcare services and optometry, as well as specialist and some allied health services [41]. Primary care in Australia is delivered through GP's who act as gatekeepers to specialist services. Patients are free to choose their primary care providers therefore, have access to services which incur no out of pocket expenses. Australia has a new National Disability Insurance Scheme (NDIS) which is being implemented. The NDIS is an insurance scheme which takes a lifetime approach to providing those considered to have a permanent and significant disability with the reasonable and necessary supports required to live an ordinary life [42]. In some states and territories, state funded community health services (often including medical and allied health services) are also available. These are generally targeted to lower income individuals/families and vulnerable population groups. The Australian healthcare system has a significant private healthcare component, including private hospitals and medical practitioners. Private hospital, dental and allied healthcare can be accessed through direct payment; alternatively cover is provided through the purchase of private health insurance and usually incurs a gap payment (i.e. consumer out of pocket expense). Private health insurance varies by socioeconomic status with 33% of the most disadvantaged quintile having private health insurance, compared with 79% for the most advantaged quintile [43].

#### 6.3.1. Access to healthcare

There are several healthcare schemes which determine access to care and the cost of services for consumers of the Australian healthcare system:

- a) Medicare benefits scheme (MBS): provides universal access to medical services but these services can be subject to additional out of pocket costs to the consumer.
- b) Pharmaceutical Benefits Scheme (PBS): the PBS provides government subsidised medications to Australian residents who have a Medicare card.
- c) Health Care Cards (HCC): HCC are available for low income earners, and reduce the cost of PBS medicines, medical appointments and other government and private services [44, 45]. HCC eligibility is based on eligibility for particular Centrelink payments; Centrelink is the Australian welfare system that provides services and payments to people on a low income or no income, and/or at times of major change [46].

#### 6.3.2. Healthcare service delivery

- Healthcare delivery in Australia varies between the states and territories. Although primary healthcare services (General Practitioner (GP) services, MBS, PBS, HCC) are

Commonwealth entitlements and funded by the Federal government, healthcare delivery is generally determined at a state level. Major responsibility for delivery of free public hospital services, including emergency departments, ambulance services, public dental care, community health, prevention, chronic disease management and mental care services lies with the States. A pluralist health care system operates in Australia. In addition to public services, private practitioners play a strong role in healthcare delivery. These services can be subsidised but generally incur additional out of pocket costs which can be substantial [43].

## 7. Methods

A mixed methods design incorporating qualitative and quantitative data collection was used to capture answers to questions contained within the MOCHA WP2 surveys (*Appendices 3 & 4*). The MOCHA WP2 surveys were adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs, and the European Survey of Change [47]. These standards address the core components of the structure and process of an effective system of care for children with complex needs. They were initially derived from a comprehensive review of the literature, expert opinion, and case studies of standards currently in use across the United States of America, with input and guidance from a working group of stakeholders including; paediatric providers, health plans, children's hospitals, families/consumers, health services researchers, and others [47]. There are 10 domains within these standards. Vignettes [48, 49, 29] were developed for children with complex, mental health conditions, using ADHD and Autism as exemplars [25]. Although the MOCHA WP2 project identified ADHD and autism as examples of complex mental health conditions [25] for this study comparison of service provision for other mental health conditions (e.g. anxiety) was also sought to provide a more comprehensive perspective of complex mental healthcare service delivery relevant to the Australian context [50].

### 7.1. Recruitment

A purposive sampling strategy using the professional networks of the Principal Investigator Harriet Hiscock (paediatrician) was used initially. Key informants [35] were identified from within professional networks of Paediatricians, Child and Adolescent Psychiatrists and Psychologists, as these are the health professionals who commonly manage complex mental health conditions in the tertiary/secondary care services in Australia. Recruitment was supplemented by snowball sampling [51] from the initial interviews. Snowballing sampling is a research strategy whereby participants involved in the study identify other people who may fit the research criteria [52]. To ensure a range of perspectives, we interviewed healthcare professionals practising in urban and rural locations, in all Australian States and territories, (except the Australian Capital Territory).

This approach was applied to gain a multi-disciplinary, quasi-national view of service delivery across Australia, given that our system is not a national system as applies in many European countries.

### 7.2. Procedures

Semi-structured interviews were conducted with 30 health professionals across Australia. Participants were informed that their participation was voluntary and unpaid. Approval was received from Human Research Ethics Committee at the Royal Children's Hospital (HREC 36217) prior to commencement of the project.

Participants were invited to address questions from the MOCHA WP2 surveys [25] relating to Autism only, ADHD only and both Autism and ADHD. Interviews lasted approximately one hour with participants interviewed either in person or by phone. Interviews were audio-recorded (with consent) and transcribed.

Transcripts from the interviews were coded and prepared for analysis using NVIVO 11.0, a software programme that allows for coding and theming of qualitative data. Transcripts were reviewed by two of the study researchers and themes discussed by the research group to achieve consensus.

### **7.3. Analyses**

Quantitative data were analysed initially using descriptive statistics; frequency and frequency percent were calculated to provide a quasi-national perspective for the MOCHA project. Responses to qualitative questions were analysed using an inductive content approach [53] whereby coding is used to identify consistent concepts emerging from the data. The objective of the analysis was to identify constructs, i.e. provisional inferences drawn from statements and observations. By using the cross-referencing ability of the NVIVO software, statements relevant to each construct were reviewed. Themes were then built using the processes of content analysis.

## 8. Key Findings - ADHD

- There are few policies or procedures at a national level in Australia, with the exception of services through the universal health care scheme (MBS) which allow simultaneous access to primary and secondary care.
- For those children prescribed stimulant medication, the requirement for script renewal (every 6 months) acts as a catalyst for ongoing screening while they are prescribed that medication. Where children are not prescribed stimulant medication, there are no policies or procedures for ongoing screening.
- Parents' play a major role in accessing care and care coordination. Their capacity to advocate for their child plays a fundamental role in both access to care and care coordination.
- There are few community based support groups specific to ADHD.
- Children like Peter (in the MOCHA WP2 vignette) would rarely be seen in the hospital system in Australia.
- Psychiatrists generally don't see children with ADHD unless there are significant mental health comorbidities, e.g. psychosis.
- Services for transition to adult care are widely considered to be lacking. Barriers include a lack of adult psychiatrists which sufficient expertise in this area and a reluctance by adult psychiatrists to prescribe stimulant medication.
- A lack of government funding limits service delivery for children with ADHD including support through the education system.

### 8.1. Screening, Assessment and referral

- There was consensus that no policies exist on a national basis to ensure a child receives ongoing preventative care, screening and checks.
- Overall the majority of clinicians agree there are no universal procedures to ensure a child receives ongoing preventative care, screening and checks. Some felt the requirements for review in relation to stimulant medication would cover this for ADHD, others felt best practice in terms of clinical care meant individual clinicians would ensure this occurs.
- It was generally recognised that children not prescribed medication may not have ongoing screening or even be treated at all.

#### Representative quotes

*"reviews are often dictated by the length of time we can prescribe a stimulant script for". (Paed 7)*

*"with ADHD prescription you're legally required as a prescriber... it's very narrow in what it requires us to do and that is the way to keep and you know, make sure it's alright. But other than that there's nothing else". (Cap10)*

- Where screening occurs, it is conducted by a variety of practitioners; paediatricians, psychologists, OTs, speech therapist, physios, psychiatrists (applicable to children with mental health comorbidities) depending on child's needs and comorbidities, (e.g. learning difficulties) and the views of the treating clinician.

- Social care providers are not routinely involved in a case like Peter. Social care screening is generally limited to child protection services, although in some states public hospitals have a social worker attached and involved in complex cases.
- There are no policies to document and communicate these screening results to parents although the majority of participants generally agreed there are procedures to ensure that parents would be informed. These are not necessarily determined by the state but individual hospitals, professional colleges and general best practice considerations.
- No policies or procedures exist to ensure the results of any screening are communicated to all health care providers. Communication depends on the practice of the treating physician and their relationship with the other service providers.

## 8.2. Access to Care

- There was an overall consensus that there is no system in place to identify all healthcare providers. Some attempts have been made and there are lists in some states provided by Health Departments (e.g. Western Australia). Although this was considered ideal, many clinicians felt it was difficult to manage and keep up to date.
- Participants expressed the view that there are no policies in place to identify all social care providers.
- There are no agreed multi-disciplinary guidelines in Australia, although clinicians mentioned that attempts have been made by the NHMRC. These guidelines were not ratified and remain in draft form. Amongst clinicians there was some uncertainty about the status of the NHMRC guidelines. The use of the UK National Institute for Health and Care Excellence (NICE) guidelines and the American College of Psychiatrists (ACP) as well as guidelines by professional bodies within Australia, e.g. Royal Australasian College of Physicians (RACP), Royal Australian and New Zealand College of Psychiatrists (RANZCP) was widespread.

### Representative quotes

*“there’s a national guideline but to my knowledge it remains in draft form”. (Cap3)*

- Many clinicians felt that multi-disciplinary *solutions* are in the best interest of the child rather than policies or procedures, which may even be detrimental.

### Representative quote

*“I think again that the multidisciplinary approach is really helpful. To be able to utilise different skill sets and do assessments across a range of domains is really important”. (Cap6)*

- The majority of respondents felt that formal training is available for parents, not necessarily specific to ADHD (e.g. Triple P parenting). Many felt that training parents was part of the role of the treating profession, e.g. paediatrician, psychologist.
- Statutory healthcare providers vary substantially depending on the State or territory in Australia. These can include tertiary-based paediatricians, psychologists, and psychiatrists (generally only where there are significant comorbidities). GP’s are funded by the government through the MBS but cannot initiate stimulant medication in most States and Territories. They can provide repeats for a script. However in Australia, ADHD is generally treated within the community sector by private providers (paediatricians) following referral from a GP. One state based Child and Adolescent

Mental Health Service (CAMHS) has a specific public health service for children with complex ADHD. However, this service sees a limited number of children relative to the prevalence in that State.

- Despite a widespread view that parents' capacity to act in relation to their children's condition was a key factor in the outcome for the child, no policies exist to assess family capacity.
- Procedures were limited to specific organisations however, most clinicians felt that it was a part of the consultation process to assess this and enact child protection mechanisms if they were sufficiently concerned.

### Representative quotes

*"I actually think the condition is not well enough understood. I think if there was a greater collective understanding of it then that might help to integrate services more. Probably the fact that there isn't any specific funding so the treatments that these kids get probably does depend on where they live and how much money the family's got, how capable the parents are of getting help for their child". (Cap4)*

*"families who are good self-advocates tend to have the best outcomes because so much is reliant on good advocacy skills by a parent or guardian". (Paed 1)*

*"In all of the developmental teams we have in [xxxxxx], we have as many social workers as psychologists. We have a bunch of social workers, and they're involved completely in the home-based assessments. They will often do family and family-functioning assessments and be involved in our feedback and goal setting things with the family". (Paed 3)*

- Professions responsible for providing health and social care after an acute episode (crisis) would be police, teachers, school principals, treating psychologists and paediatricians, psychiatrists, child protection workers and occasionally social workers depending on the location and circumstances of the child. The most likely health professional to deal with a child after the crisis was the practitioner/clinician the parent felt most comfortable working with. Clinicians felt that parents also carried a large amount of responsibility when there was an acute episode.
- Overall, no policies exist across Australia for ensuring parents have an overview of the healthcare system. This is exacerbated for parents of children with ADHD where support organisations are very limited.
- Overall, there are no policies to ensure that children are treated by the same healthcare or social care professional every time. Where this does occur, it tends to be due to the size of the institution (e.g. small hospital) or organisational guidelines or in private practice, but is not consistent even within an individual state.
- Simultaneous access to primary and secondary care occurs as part of Australia's universal health cover- MBS. Universal health cover is considered the greatest facilitator of this access.
- Issues that hinder access include out of pocket costs, long waiting lists in hospital outpatient clinics, lack of available staff in certain area (i.e. workforce supply).
- Transportation to care services is generally by parents without support from the state. In some cases, assistance is provided by the state if the family is eligible or by other professionals involved with the management of the child, e.g. rural families can apply for an allowance to get to care services and in some areas the principal of the school or the

healthcare provider may provide transport. However, this is clinician/school dependant and not part of any formal system.

- No national policy exists for either culturally or linguistically appropriate information although individual hospitals and health departments do have requirements. Training in this area is mandated in public services in some states however, the same requirement does not exist within the private sector, a significant part of health care delivery in Australia.

### 8.3. Care Coordination

- Participants identified that there are no policies promoting access to care coordination or procedures for children with ADHD.

#### Representative quotes

*“the fact that Australia has much more pluralistic healthcare system .....than may occur in some other countries, that's the downside. It has many upsides of course but the downsides are that it's much more variable, and it's harder to come up with coordinated plans”. (Cap 9)*

- There is no specific (formalised) care pathway for children with ADHD. Any guidance is influenced by requirements related to prescription.
- There are no formalised procedures to ensure a written personalised plan is developed but many participants felt that that would frequently be standard practice for the treating clinician to provide some guidance in writing, following a consultation.
- If a written plan is developed, it is generally developed in conjunction with the child's parents /guardian and sometimes other healthcare professionals.
- Where there are written personalised plans, they would generally include developmental checks, mental health comorbidity checks, physical health checks, vision checks. Sometimes hearing is assessed. Social health would generally be part of the discussion between the clinician and family.
- Discharge is generally arranged by a case co-ordinator rather than someone in a specific role of discharge planning coordinator. It was generally agreed that it is unlikely that the child in the vignette scenario would be treated at all in a hospital setting in Australia.
- Comorbidities are generally managed by the treating practitioner (e.g. paediatrician) with referral if considered appropriate. Frequently, a mental health comorbidity would be the factor that would be the catalyst for the child to access services in a tertiary (public) setting, not a diagnosis of ADHD.

#### Representative quotes

*“I'm pretty sure that CAMHS policy in this state only talks about the treatment of ADHD and Autism where there is what they call, a significant level of mental health comorbidity. So someone has only ADHD or someone has only Autism, our CAMHS would not provide a service to them, they would be out of scope”. (Cap2)*

*“If it is comorbid ADHD the paediatrician would manage the ADHD, if it's anxiety emotional behavioural distress psychologists would come involved and work with the paediatrician and family if it required, if it becomes psychotic or unmanageable at that level they go to a child psychiatrist”. (Psy1)*

*“what they get cared for in their child psychiatry treatment is their comorbidity, they don’t get treated for their Autism or their ADHD really”. (Cap10)*

*“and child and adolescent mental health services, but that’s usually for children with quite significant comorbidities”. (Paed1)*

#### 8.4. Community based services and supports

- Few community based organisations specific to ADHD exist to support families however, Non-Government Organisations (NGO) assist in a general way (e.g. respite if eligible).
- Family advocacy groups have a very limited role in making recommendations for children with ADHD as very few advocacy groups exist for this condition.
- Siblings and parents have access to psycho-social support through the mechanism of the Better Access scheme and Access to Allied Psychological Services (ATAPS) scheme which provide subsidies for psychological support, and fall under the MBS. Barriers to accessing this occur due to a limited number of sessions included under these schemes, out of pocket costs for psychologist’s or other allied health professional’s appointments and insufficient psychologists/other allied health professionals in some locations.
- Respite care is available on a very limited basis. Some services are provided by the state, some by provided by NGOs, with a few respondents suggesting that private organisations also provided services. Most felt that the number of services was inadequate and a family needed to be desperate to access respite care.

##### Representative quotes

*“for ADHD respite care would be really around other social risk factors where there might be protective concerns about a child”. (Paed1)*

*“they’re likely to have other comorbidities it would be very unlikely to have only ADHD that precipitates that sort of pathway”. (Paed1)*

- Most participants felt that children did receive educational interventions but the degree and quality depended on school, principal, teacher and location. This is particularly as ADHD is not funded for educational support.

##### Representative quotes

*“families can request an individualized education program or an individualized behaviour support program but most schools don’t automatically provide this for children with ADHD because it’s not one of the conditions listed under the program for students with disabilities. But schools are obliged at a policy level to provide it if families do request it”. (Paed1)*

#### 8.5. Family professional partnership

- Most clinicians felt that parents were not involved in the development of policies and procedures or national quality improvement initiatives.
- Parents are not involved in the review of whether materials are culturally or linguistically appropriate. There was recognition that most hospitals had consumer representatives as part of their satisfaction feedback mechanisms and this issue may be

included in that process. Little consideration is given to providing information in indigenous languages.

### **Representative quotes**

*“in public mental health services where it’s one of the national criteria, one of the criteria of the national standards to ensure that carer’s and parents contribute to service development”. (Cap3)*

## **8.6. Transition to adulthood**

- Consistently participants felt that the transition to the adult health sector was a concern and there are no consistent policies or procedures for transition.

### **Representative quotes**

*“I just think there’s a huge sort of gap there in terms of what we provide adults with developmental disorders and you know there’s a huge overrepresentation of adults with developmental disorders in our prison systems and .....they don’t have access to a whole range of services that other people do, even you and I”. (Psy9)*

*“...at the moment that’s the biggest point of weakness that I see in our system”. (Paed 2)*

*“this is a huge issue there is a real bottle neck.....especially secondary or tertiary care providers who can take on young people with ADHD”. (Paed1)*

*“I’m probably, at the moment, seeing six or seven young people who are over 18 and less than 23, which is our legal cut-off for not seeing them anymore, they’re really easy to look after, but I can’t find anybody to transition them to”. (Paed 7)*

- Key barriers include a lack of adult physicians and psychiatrists with expertise in ADHD and the reluctance of adult psychiatrists to prescribe stimulant medication due to issues such as stigma.

### **Representative quotes**

*“there is a very small number of psychiatrists who do it and then sometimes GPs take it on but a lot of the time people end up stopping their medications”. (Paed1)*

*“because of the restrictions around that medicine, we need to find an adult psychiatrist who’s willing to prescribe for them and take them on. Locally, that’s a really, really big problem, and there are only a couple of adult psychiatrists who are happy to do that work”. (Paed 7)*

## **8.7. Quality Assurance**

- No national policies exist for quality assurance procedures but within individual organisations procedures exist. These are not universal and not dictated by the state.
- Rarely are data collected on the experience of care from the parents or siblings or health care professionals unless it is part of a research project. No data are routinely collected from the perspective of the healthcare provider.

### **Representative quotes**

*“there are some quality assurance procedures, not policies, around peer review for assessment. Not so much the ongoing care”. (Paed3)*

## 9. Key Findings - Autism

- There are national policies regarding funding for children with Autism (limited to children under 7) but not necessarily service delivery and care coordination.
- The level of support typically depends on the age of the child and capacity of the parents. Children like Mark with parents who are alert to the changes in behaviour and condition would be supported through government funding for early intervention programmes, but others may not if they do not seek a diagnosis.
- Children under 7 who have an Autism diagnosis have been able to access funding under the Helping Children with Autism package (HCWA) . However, Australia is introducing a National Disability Insurance Scheme (NDIS) and the HCWA funding will be withdrawn as this is rolled out across the country. This change has the potential to impact some families negatively as well as impacting other families positively. Additional support through MBS is available for 20 therapy sessions for children up to age 13. If diagnosed after 7, support is frequently lacking.
- NDIS will be a significant change for the management of Autism, but there is uncertainty about the details of how this will impact children and families.
- Autism services have typically been provided within the disability sector rather than healthcare services. This can create a barrier to continuity of care.
- It is recognised that the advocacy efforts of parents have influenced the government based funding provisions.
- Funding supports a variety of intervention therapies for children but is not necessarily linked to evidence based therapies.
- Community service organisations operate in all states and territories of Australia to support and assist families with navigating the systems involved in providing access to care for children with autism.
- Funding for educational support is available for children diagnosed with Autism thereby ensuring those that qualify for the funding will be assured some educational interventions.
- Successful transition to adult services is more likely for children with a level of disability that wants education through the special school sector. For children with a milder condition, services are frequently lacking.

### 9.1. Screening, Assessment and referral

- Overall consensus that the main focus of national policies and procedures for children with Autism is focused on diagnosis. There are no national policies to ensure a child receives *ongoing* preventative care, screening and checks.
- Some participants felt best practice in terms of clinical care meant individual clinicians and therapists would ensure that this happens, particularly if the child was receiving an early intervention funding package through HCWA. As this funding package is being wound down with the ongoing implementation of the NDIS, uncertainty exists about how children and families will be impacted.

#### Representative quotes

*“there is no measures that are used for screening and there’s no timeline or you know state things that state when people should be reviewed and how often they should be reviewed”. (Paed2)*

- Some participants felt best practice in terms of clinical care meant individual clinicians and therapists would ensure that this happens, particularly if the child was receiving an early intervention funding package through HCWA. As this funding package is being wound down with the ongoing implementation of the NDIS, uncertainty exists about how children and families will be impacted.

### Representative quotes

*“there's nothing mandated, it's really parent driven which I really like. I think that's the great thing about the FaCHSIA money that the parents are driving the process and they've got to trust their providers and figure out a path. Really Autism is such a multifaceted thing and the picture changes so much over say the first 10 years of life”. (Psy 3)*

- “it's the paediatrician that coordinates the care, but there's nothing mandated or there's no, it's going to become more difficult with the NDIS as well when they change the range of NGOs and there's actually not one policy or there's not one document that follows a child around or that dictates how we should communicate or case conference or share information even, so I think it's a pretty big issue”. (Paed 8) Where screening occurs, it is conducted by a variety of practitioners; paediatricians, psychologists, OTs speech therapist, physios, psychiatrists (limited to children with mental health comorbidities) depending on child's needs and comorbidities, e.g. learning difficulties.

### Representative quotes

*“...speech pathologists, and the OTs, and the psychologists. So, while they're providing their intervention, I suppose they're also monitoring progress as they go along, reviewing how things are going”. (Paed 7)*

- There are no policies to document and communicate these screening results to either parents or other healthcare providers although the majority of clinicians agreed that parents would be informed. The transfer of information to other healthcare providers was more likely to depend on the relationship between clinicians rather than a more formalised system.

## 9.2. Access to Care

- Overall there is no system in place to identify all healthcare providers. Autism support organisations (NGO's) e.g. Amaze (in the state of Victoria) provide lists which are considered comprehensive, and individual clinicians have their own networks of colleagues where they refer. Some state Health Departments have also attempted to provide lists although they acknowledge it is difficult to keep these lists updated.
- No policies exist to identify all social care providers.
- Participants felt that here were no multi-disciplinary guidelines used across Australia and suggested specific requirements may even be detrimental to the provision of care.

### Representative quotes

*“What I would to hate to see as an outcome is we would have to go around kind of filling out forms once a year for children with autism and saying they haven't done this and they haven't done this, and they have done this,.....because I think the system is so stretched that we haven't got time for procedures, and it sounds*

*counter intuitive and we'd probably be better off if we did have a few procedures, but putting the procedures in place might actually take away from kids first rather than actually adding to it". (Paed 2)*

- Multi-disciplinary solutions were considered valuable whether there were guidelines or not.

### **Representative quotes**

*"in an ideal world there would be a collaborative relationship between the paediatric team and the mental health team in [xxxxx] and in my ideal world that would include shared care and multidisciplinary assessments in collaboration, because there's an enormous amount of children in need". (Paed 6)*

- The majority of clinicians felt that formal training is available for parents, including some programs specific to parents of children with Autism, in addition to general parenting programmes. Concerns were expressed about the actual number of parents were accessing training and issues linked to fidelity of the intervention. Many felt that training parents was part of the role of the treating profession, e.g. paediatrician, psychologist.
- No policies exist to test families' capacity, however, informal procedures via the treating physician or child protection mechanisms occur. Parental capacity is recognised as a key ingredient in the outcomes for child.

### **Representative quotes**

*"It would be really good if there was a standard of what you needed to provide and how much care the child needed... But of course every child is so independent and it is so dependent upon their families capacity to provide services themselves". (Psy 4)*

- Generally participants felt that it was the responsibility of services outside the healthcare system to manage crisis scenarios, frequently parents.

### **Representative quotes**

*"the family is responsible to try and sort out if anything goes really wrong, as well trying to sort out what on earth to do for their child, but it depends on the system they're involved in. It might happen that the particular school they attend is very good at dealing with a behavioural crisis." (HSM 1)*

- Overall, there are no national policies for ensuring parents have an overview of the system. However, there are some specific structures in place (e.g. access to Autism Advisors if families have access to the Helping Children with Autism package) where a major aspect of their role is to assist and support families to navigate the healthcare and disability systems.

### **Representative quotes**

*"again once, you get a diagnosis of autism, you are on your own to chart to your own course". (Psy 2)*

*"...under the helping children with autism package, the autism advisors have been a decided success nationally, whereby there has been a regular place where people can get information and a pathway for how they can work their way through, at any point,..... they can keep coming back so I think there is, under the helping children with autism package, something that has been established. It has made, particularly, a big impact on school life and early intervention life. So that, that's probably the most, one of the more successful pathways that has been established in the field of disability". (HSM 1)*

- Overall, no policies exist to ensure that children are treated by the same healthcare or social care professional every time, although where there are funding packages in place this may occur by default.
- Access to primary care and secondary care simultaneously is provided though the MBS.
- Issues that hinder access include out of pocket costs, long waiting lists in hospital outpatient clinics, lack of available staff in certain areas (i.e. workforce supply).
- Transportation to care is generally by parents without support from the state. In some cases, taxis or buses are provided to access special schools and rural families can apply for an allowance to get to care services. In some areas, the principal of the school or the healthcare provider may transport but this is clinician/school dependant and not part of a formal system.
- No national policy exists for either culturally or linguistically appropriate information although individual hospitals and health departments do have requirements. Publicly funded services such as hospitals generally require cultural training but the private sector is not subject to the same requirements.

### 9.3. Care Coordination

- No national policies exist promoting access to care coordination. Autism has generally been managed through the disability sector in Australia. A lack of coordination of services within and between Government departments has frequently exacerbated issues of care coordination.
- Procedures for care coordination exist where children with autism have access to HCWA funding. Early intervention programs have a degree of care coordination.
- The change to NDIS has the potential to reduce the level of care coordination as parents are the key decision makers in the way that funding is distributed.
- Clinicians expressed concern that there is no requirement under NDIS for healthcare providers to be consulted on treatment options, although many felt that parents would follow this course of action without a legal requirement.

#### Representative quotes

*"I think one of the real challenges within service provision within this country at the moment is going to be how we integrate and inter-relate with NDIS services". (Paed 13)*

*"I think in the next 10 years there's a chance for it to evolve into something positive rather than not, so I think that's an opportunity, but I think at the moment it seems, at least to the paediatricians on the ground, it seems as though we haven't been involved at all in that NDIS discussion and we're not being invited to the table when care is being planned much at all". (Paed 7)*

*“the truth is there will never be a one-system-fits-all. So I despair almost at the difficulties of people at low SES and English as a second language in being able to compete with the articulate, tertiary-educated parents who can convince the planners to give them mega-packages.” (Paed 4)*

- Discharge is generally arranged by a case co-ordinator rather than a specific role of discharge planning coordinator. It was generally agreed that it is unlikely that the child in the vignette would be treated at all in a hospital setting in Australia unless there were comorbidities which had brought the child to the hospital setting.
- Comorbidities are generally managed by the treating practitioner or staff in the applicable setting. As outlined above, the comorbidity would be the factor that would cause the child to go into a tertiary setting not a diagnosis of Autism.

### **Representative quotes**

*“If it’s happening... at school often those will be dealt with initially. I suppose there is a tiered system. And if they have guidance officers or welfare officers provide programs for those children and then the next level would be the school psychologist and then the next people up would make a referral up for the CAMHS intervention so to get into CAMHS usually you’ve gone through those other steps before you can access long term therapy through CAMHS”. (Paed 2)*

*“for kids with mental health problems, the situation is more difficult. Often because they’re not properly identified or assessed and because of diagnostic overshadowing. If the child, for example has got difficult behaviour, for many it’s regarded as just due to their autism, when in fact it might not be, it might be due to an anxiety disorder or ADHD or a schizoid type of disorder or another mental health problem”. (Cap 8)*

- There is no specific care pathway for the treatment of children with autism.
- There are no formalised procedures to ensure a written personalised plan is developed but many felt that that would be standard practice to work with parents on a longer-term approach to therapy and this would often be in writing.

## **9.4. Community based services and supports**

- Community based organisations are very important in Autism. Services are typically provided by NGO’s and private practitioners and each state would have access to an Autism specific community support organisation as well as other NGO’s offering community services.
- Family advocacy groups are a key component of community based supports in autism and have some role in making recommendations about services and supports. Autism advisors (generally provided through community support organisations) act to support parents in accessing services for their children and navigating the various systems involved in providing care.
- Siblings and parents have access to psycho-social support through the mechanism of the Better Access scheme which provides a subsidy for psychological support, and falls under the MBS. Barriers to accessing this occur due to a limited number of sessions included under this scheme, out of pocket costs for psychologist’s appointments and insufficient psychologists in some locations.

- Respite care is available on a limited basis. Some services are provided by the state, some by provided by NGOs, with a few respondents suggesting that private organisations also provided services. Most felt that the number of services is inadequate and a family needed to be desperate to access respite care.
- Where children have an Autism diagnosis most felt that children did receive educational interventions due to the funding attached. The extent and quality of the intervention depended on school, principal, teacher and location.
- Each state has an Autism Specific Early Learning and Care Centre (ASELCC) however, places are limited.
- Special schools for children (sometimes specifically for autism) were considered to generally be of high quality and provide good support for children. However, many children are educated within mainstream schools and the degree of support in this setting was considered variable.

### Representative quotes

*“getting the kids with adequate supports in the mainstream schools I think is a really positive thing, if it can be done well, because in the end these kids have to live in the real world and I think to try and help them with their education and that kind of stuff is crucial with that. I mean supports for the family, I think there is a lot more information now than there used to be, it's still not enough probably but I think there is more in the way of support services and things so the potential is there to access those services”. (Cap 7)*

*“I hear from some kids that they get weekly visits from [xx] to the school, I don't know how they are getting that. So then I say to one of my friends you might want to ring [xx], and see if they can provide you with in school support. Then they do that and they go, ah no we can't do that. Well I know you're doing it for somebody else, why aren't you able to provide it for this child. It seems all a bit random”. (Psy 4)*

#### 9.4.1. Family professional partnership

- Parent involvement has been a strong catalyst for the development of policies and procedures in Autism, particularly lobbying for funding.
- Parents are involved in the review of materials to determine if they are culturally or linguistically appropriate generally through support organisations or hospital consumer organisations.

### Representative quotes

*“I know in CAMHS we have consumer advocates and for the last 20 years in our service the consumer advocates have been parents of children with Autism and they've played a massive role in developing policies around inclusion and accessibility for indigenous people and accessibility for non-English speaking parents”. (Cap 3)*

#### 9.5. Transition to adulthood

- There are no consistent policies or procedures for the transition to adult services.

- NDIS may change this for those that are eligible, as it will be based on lifelong functional impairment.

### **Representative quotes**

*“So people who go through specialized autism schools or special schools; .....there’s a slightly better level of support in terms of moving out in the community, it’s a bit more preparation for life skills and for integration into, into employment, but for the higher functioning children whom leave secondary schools there’s almost nothing apart from those who might go to a TAFE or a university where there is a disability advocate.....at the moment that’s the biggest point of weakness that I see in our system”. (Paed 2)*

*“there’s just no systems in place when kids with autism finish year 12; they fall off the cliff really there is no help they end up disengaged, being at home and there are no mechanisms to help them get or very few mechanisms and not good ones to help them get employment”. (Psy 9)*

*“adult mental health care of people with Autism is a freaking mess.....” (Cap 2)*

*“the big issue is the transition to adult services: the lack of adult services and what happens to them and where they go as adults, that’s a big major issue”. (Paed 8)*

*“As far as the autism community goes, again, a lot of the private psychiatrists seem to have a view that as soon as somebody has what they would call a disability, that they’re too hard to look after or that you need some sort of specialist training to be able to deal with somebody with a disability”. (Paed 7)*

## **9.6. Quality Assurance**

- No policies exist for national quality assurance procedures but with certain organisations procedures exist, particularly linked to funding.

### **Representative quotes**

*“early intervention centres and receiving funding from the department of early education there would be a whole lot of policies and procedures that they have to abide by so it depends where the funding comes from, which resource”. (Psy1)*

- Rarely are data collected on the experience of care from the parents or siblings or health care professionals, although this may occur through specific research projects. A Cooperative Research Centre (CRC) specifically for Autism has significant funding and was identified as an opportunity for research into this area.

## 10. Convergence on findings

- National policies and procedures for both conditions are limited to those provided through Australia's universal healthcare system - MBS. This is in part due to the structure of Australia's healthcare system, whereby the funding for different sectors of healthcare is provided by both the Federal government and State and Territory governments.
- The MBS facilitates access to primary and secondary providers simultaneously. MBS also provides subsidised psychology support for families and siblings but is limited in number and dependent on GP's or specialist doctors (psychiatrists, paediatricians) providing referrals. Additional costs over and above the subsidy and workforce supply are also factors identified as barriers to accessing services.
- Access to care is substantially influenced by the capacity and resources of parents.
- There are no multi-disciplinary guidelines applicable nationally. Reference to guidelines from international organisations and professional bodies was common.
- Multi-disciplinary solutions were perceived as optimum in care for both conditions.
- Many practices occurred linked to perceived best practice by the clinician.
- Transition to adult care is problematic for both conditions. A lack of adult clinicians with expertise in either ADHD or Autism is perceived as a major barrier.
- The impact on siblings has little consideration in either condition.
- There was little evidence of national quality guidelines, although guidelines specific to individual organisations exist.
- Transport to care services is generally provided by parents without support from the state.

## 11. Dissonance on findings

- Children with Autism have far greater recognition of the needs and complexity of services required than those with ADHD.
- Autism has substantial early intervention funding attached to diagnosis if under 7 years of age. ADHD has no direct funding.
- Parents have been stronger advocates for funding for their children in Autism than ADHD and have had greater success in lobbying for Government funding.
- Autism has substantially better community based networks for parent support and NGO support than ADHD.
- The education system has a strong role to play in both conditions, but is substantially more supported in Autism compared with ADHD due to Autism being a funded diagnosis for learning support payments.
- Autism has generally been managed in the Disability sector whereas ADHD is managed through the healthcare system.
- NDIS will change the shape of integration of care but it is uncertain in what way, e.g. who will get funding, who will miss out, although it is recognised that children with Autism may be more likely due to previous Government funding transitioning to the NDIS.
- Policy requirements for oversight of stimulant prescription provides a de facto catalyst for ongoing screening for children with ADHD (and on medication). Without this catalyst there are no consistent policies or procedures for ongoing screening for children with autism.

## 12. Survey of change - ADHD

### 12.1. Section 1: Current state of development

Most significant changes:

- Access to prevalence data identifying the extent of these conditions in Australia –Young Minds Matter survey
- Disintegration of school support services and lack of recognition of the need for integrated care including psycho-social support for ADHD (not just about medication)
- The Better Access scheme has increased ability to access government funded psychology services
- Shift in parent desire from an ADHD diagnosis to Autism (funding related)
- Increasing recognition that ADHD and learning disorders are common and prevalent conditions
- Long acting medications which has made it easier for children at school

Evaluation of progress: Remained the same

Main barriers to integration:

- Cost of services to parents
- Public mental health system limiting its scope of practice due to (lack of) funding
- Lack of recognition that ADHD causes significant impairment
- Diagnosis not recognised as a neuro-biological condition by some
- Lack of specialist service focus on lifelong persistent, chronic conditions (much more on intervention based strategies)
- NDIS is potentially a barrier to integration (focus on permanent impairment)
- Access to expertise skilled in treating adult ADHD
- Failure by government to recognise that ADHD is a common childhood disability, therefore lack of publically funded services available
- Time constraints on therapists and carers
- Lack of sufficient funding for proper case management by paediatricians
- Lack of child psychiatry services

Main opportunities for integration:

- Co-location of services e.g. Child Development Units
- Co-operation between different specialists (paediatricians, psychiatrists)
- NDIS
- Application of technology, e.g. teleconferencing, email, apps
- Willingness of government to at least have some dialogue about developmental problem creates an opportunity for advocacy
- The Developmental paediatricians group could advocate for the use of standards of care e.g. NICE guidelines etc.
- Medicare item numbers for case management
- Some form of template for service integration that gets modified according to the needs of the child

- More thought about integration from childhood into adulthood
- Redistribution of funding for services in rural /regional areas to reflect the numbers of children living in those areas
- Adequate supports in schools
- Support for GP's in the management of these conditions
- More enthusiasm and recognition of the need for individual practitioners about the need for integrated services.
- Maps/flow charts that make the navigation of services following diagnosis easier for parents and clinicians.
- Improved co-ordination across, health (Medicare), disability (NDIS) and education through a better interface between these groups to stop children and adolescents falling through the gaps
- Increased training opportunities and professional development in this area as well as students being trained at university.
- Initiatives that support clinicians, schools and parents working together
- Working with parents more and increased training for parents, including around the possibilities once they reach adult hood.
- More funding for research
- Multidisciplinary teams
- Improving services for adolescents and then adulthood.

## 12.2. Section 2: Policy and socio-cultural issues

Strategies for improving political awareness

- Typically clinicians identified "None, or none that I am aware of"
- Local initiatives by NGO's such as Learning and Attentional Disorders Society of Australia (LADS)

Funding initiatives

- None specifically for ADHD, funding now moving away from a diagnosis based model
- Possible eligible families under the NDIS (uncertain)

Discussion, debate and controversy

- Incessant discussion about over medicalisation of ADHD
- Lack of adult physicians that will treat adult ADHD and how to manage transition
- ADHD has gone off the radar, not really talked about

## 13. Survey of change - ASD

### 13.1. Section 1: Current state of development

Most significant changes:

- NDIS
- Autism Advisor service supporting families
- Recognition by schools that these children need good management

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- Increases in the services available for children with Autism
- Choice and Partnership Approach (CAPA) model for mental health conditions (used in some CAHMS)

Evaluation of progress: Improved

Main barriers to integration:

- Cost to parents
- Public mental health system limiting its scope of practice due to (lack of) funding
- Role of the private sector services and their need for profitability
- Treating professions working in isolation physically and professionally leads to families getting different information from different providers and working out what they want to believe
- Burden of care seems so great it seems that no amount of support will ever be sufficient
- Insufficient resources to support these children within mainstream schools and a lack of autism specific schools
- Lack of clear referral pathways, guidelines and protocols
- Australia's pluralistic healthcare system
- Lack of engagement with local healthcare providers when system level changes are designed and implemented (particularly in rural and regional areas) leading to a lack of understanding of location specific issues which can impact service delivery
- Silos within government departments
- Lack of robust evidence-based treatments for Autism
- NDIS may be a barrier for some children
- Differences in service delivery in regional/rural areas compared to urban area

Main opportunities for integration:

- NDIS
- Application of technology, e.g. teleconferencing, email, apps
- Willingness of government to at least have some dialogue about developmental problem creates an opportunity for advocacy
- The Developmental paediatricians group could advocate for the use of standards of care e.g. NICE guidelines etc.
- Medicare item numbers for case management
- Some form of template for service integration that gets modified according to the needs of the child
- More thought about integration from childhood into adulthood
- Redistribution of funding for services in rural /regional areas to reflect the numbers of children living in those areas
- Adequate supports in schools
- Support for GP's in the management of these conditions
- Co-location of services, e.g. Child Development Units
- More enthusiasm and recognition of the need for individual practitioners about the need for integrated services.
- Maps/flow charts that make the navigation of services following diagnosis easier for parents and clinicians.
- Improved co-ordination across, health (Medicare), Disability (NDIS) and education through a better interface between these groups to stop people falling through the gaps.

- Increased training opportunities and professional development in this area as well as students being trained at university.
- Initiatives that support clinicians, schools and parents working together
- Working with parents more and increased training for parents, including around the possibilities once they reach adulthood.
- More funding for research
- Multidisciplinary teams
- Improving services for adolescents and then adulthood.

## 13.2. Section 2: Policy and socio-cultural issues

Strategies for improving political awareness;

- Lobbying by parents, support from a high-profile politician with a child with autism
- Lobbying by NGO's e.g. ASLEC, Autism Aspergers Advocacy Australia (A4)
- Patient advocacy
- Funding for a CRC to support research on a national level in a more coordinated way
- Synthesis about the importance of early intervention and providing that information to government (relevant to all conditions)

Funding initiatives;

- Funding for CRC
- NDIS
- HCWA was a great funding initiative in 2008 but being wound down

Discussion, debate and controversy;

- Changes to the DSM 5 criteria for autism diagnosis
- Controversy around the causes of autism
- Lack of evidence for some of the treatments which are Government funded
- Increase in incidence reported. Is it a real increase in prevalence or over diagnosis?
- Schooling and how best to cater for children with autism in a mainstream school (particularly if they are difficult)
- Need for autism specific schools
- Management of autism in adulthood and lack of services.
- NDIS

## 14. Summary of key issues, possible solutions and additional observations identified from a national qualitative study

### 14.1. Key Issues

- **Few national policies (legal frameworks) or procedures operate across Australia.** This is in part due to the structure of the healthcare system in Australia whereby responsibility is shared between Federal and State Governments. Primary healthcare services (General Practitioner (GP) services, MBS, PBS, HCC) are Commonwealth entitlements and funded by the Federal government, whereas healthcare delivery is generally determined at a state level. There are more national policies and procedures in relation to ASD than ADHD.
- One national policy that does apply is **universal health insurance – Medicare Benefits Scheme (MBS)**. Despite some limitations Medicare was considered to underpin access to care and is considered a key facilitator of access to both primary and secondary care.

#### Representative quotes

*“I do believe the Medicare system here is actually overall not broken, it’s a good system, it’s been shown to work for many, many different medical conditions and I think everyone knows how it works.....I think the Medicare system is a good structure in keeping the primary care provider involved in the loop.” (Paed 5)*

The introduction of a National Disability Insurance Scheme (NDIS) is also a national policy which when fully implemented, will apply across the country.

- Access to care is substantially influenced by the capacity of parents.

#### Representative quotes

*“families who are good self-advocates tend to have the best outcomes because so much is reliant on good advocacy skills by a parent or guardian.” (Paed 1)*

*“basically up to parents and to some extent the profile of the child as to who people will access.” (Paed 2)*

- The system of care is **hard to navigate** for parents and clinicians.

#### Representative quotes

*“It’s a hit and miss thing depending on who they are seeing” (Psy 1)*

*“parents find it extremely confusing and constantly I find families that I feel like, you shouldn’t have to reinvent the wheel.” (Psy 4)*

- While government departments are frequently thought to operate in silos (lack of coordination, shared resources, etc.), **silos are operating as a barrier in many areas** in the management of these conditions, not just government.

#### **Representative quotes**

*“that’s been also a big barrier that, that whole discipline of [ADHD] research and clinical practice has almost developed in complete parallel to Autism and yet we know that 3/4 of kids will have ADHD and a 1/3 of children with ADHD will have Autism, that’s crazy.” (Psy 1)*

- **Multi-disciplinary solutions** were seen as key to improving outcomes in Australia.

#### **Representative quotes**

*“I think again that the multidisciplinary approach is really helpful. To be able to utilise different skill sets and do assessments across a range of domains is really important.” (Cap 6)*

- The **introduction of the new National Disability Insurance Scheme (NDIS)** in Australia is clearly a substantial change, however the impact of the NDIS and how it will operate in specific situations is very uncertain.

#### **Representative quotes**

*“..... [parent education] is still rolled out for free here..... but I think we’re all wondering what the impact of NDIS will be with regards to that.” (Paed 10)*

- The issue identified as the most problematic was the **transition to adult care** for both conditions.

#### **Representative quotes**

*“.....at the moment that’s the biggest point of weakness that I see in our system.” (Paed 2)*

## **14.2. Possible solutions**

- **Empowering parents** to support their children was seen as critical to ensuring continuity of care. This means providing tools, resources and support. Strengthening education systems to work with the healthcare system and parents was also a key theme.

#### **Representative quotes**

*“What I can do in half an hour a month is nothing compared to what a parent can do.” (Paed 9)*

- Where possible the **co-location of services** were perceived to have benefits over and above accessibility.

#### **Representative quotes**

*“I think the barriers are the lack of everybody being sited together and the fact that all of these different professions and craft groups work in their own little bubble.” (Paed 6)*

- **Greater cooperation between service providers (particularly between medical specialists)** where there are comorbid conditions (e.g. Paediatricians/Child and adolescent psychiatrists/Psychologists/Speech therapists/GPs/Social workers) is necessary and beneficial. Where this is occurring clinicians felt that outcomes were improved.

#### **Representative quotes**

*“we meet four weekly with the psychiatrist and their social workers and psychologists.....that one on one chat sort of helps to break down those barriers.” (Paed 13)*

- Given the large distances that can occur between services in Australia, physically being situated in close proximity can be difficult. However, other mechanisms were discussed including the **role of technology** in case management.

#### **Representative quotes**

*“we're videoconferencing schools actually to have them understand what's required and give them support in helping those kids at school. It's not difficult at all, you just have to be used to it.” (Paed 12)*

- Increasing the level of knowledge within the healthcare sector for the management of children with ADHD and Autism will strengthen the overall system of care. **Capacity building by incorporating knowledge into training** for both paediatric and adult specialists (as well as GPs) was seen as an opportunity to build a more sustainable knowledge base.

#### **Representative quotes**

*“I think that there should be an expectation that all clinicians who go and work in child and adolescent mental health services receive in-service training about working with intellectually/developmentally disabled people, as they receive training about working with different cultures and different linguistic groups.” (Cap 5)*

### 14.3. Additional observations about conducting cross-country comparisons

- Even when utilising rigorously designed international surveys and methodologies, **assumptions occur when comparing ‘best practice’**. In Australia, children with ADHD and Autism are typically not seen in public hospital mental health services (i.e. Child and Adolescent Mental Health Service (CAHMS)) unless they have a comorbid mental health condition which impacts the child substantially (and falls within the scope of the service). Therefore improving service delivery and outcomes needs to be structured in line with the overall health care system.

#### Representative quotes

*“the assumption in this is that Autism and ADHD are mental health conditions that are going to be treated in the mental health system. That is not what usually happens in our country or our state.” (Cap 2)*

- The **cultural context of the survey country** impacts the interpretation and outcomes. For example, the introduction of additional policies and guidelines may not always change clinical practice and improve outcomes for children in Australia.

#### Representative quotes

*“There might be [guidelines]. If there are, I don't follow them” (Paed 12)*

- In the Australian context the challenges of service delivery in regional, rural and remote settings are a key focus of governments. However, this study found that some of the key potential solutions (co-location, cooperation between specialists and service providers, utilisation of technology) were already operating by default in some **regional areas** due to proximity and relationships. This highlighted **the importance of focussing on what is working well and what can be learnt from those situations.**

#### Representative quotes

*“for a paediatrician who works in a smaller community it's possible to know all the networks, be familiar to set up a reasonably good system for children.” (Paed 2)*

- This study also found **that good models of care exist for children in some physical health conditions** and these can be drawn upon to improve aspects of care for children with complex mental health conditions.

#### Representative quotes

*“They have nurse navigators for diabetes, but we're getting them for Autism, which is a big leap forward.” (Paed 3)*

In summary, delivering quality care for children with these complex mental health conditions is a global challenge. Despite wide variation across the States of Australia there are some well-

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functioning systems of care. The challenge is to **consolidate a knowledge base and identify effective solutions** which can be extended across Australia.

## SECTION C: Convergence of findings and future visions

### 15. Convergence on European and Australian findings on ASD

There was a large amount of convergence between the European and Australian findings from the *Standards for Systems of Care for CYSCHN* and the *European Survey of Change*. The key areas of convergence were:

Convergence	Barriers	Facilitators
<b>Screening, assessment and referral</b>	Main focus of national policies and procedures is on diagnosis. Need for national policies and procedures for ongoing screening and preventative care.	
<b>Access to care</b>	Lack of system to identify all healthcare and social care providers. Shortage of funding, available staff, specialists and expertise. Fee-based care.	Parents' involvement. Universal health cover facilitates simultaneous access to primary and secondary care
<b>Care coordination</b>	No national legislation promoting coordination between sectors. Lack of funding	Parents' involvement.
<b>Community-based services and support</b>		Key role of community-based supports, especially family advocacy groups
<b>Family professional partnership</b>	Family can access psychosocial supports restricted by out of pocket costs, shortage of specialists, etc.	Involvement of parents and advocacy groups
<b>Transition into adulthood</b>	No consistent policies or procedures for the transition to adult services	
<b>Quality Assurance</b>	No national policies or universal procedures. Data rarely collected	
<b>Discussion, debate and controversy</b>	Issues around "inclusion" of children with ASD in mainstream schools and the need for autism specific schools	

Figure 15.1: Summary of convergence of European and Australian findings for ASD

The key areas of difference were:

Divergence	Australia	Europe
<b>Screening, assessment and referral</b>	No formal systems for communication of results to parents or other healthcare providers	Collaboration between professions for screening and preventative care in several countries

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<b>Access to care</b>		
<b>Care coordination</b>	Child seen by CAMHS only if significant comorbidities, with no care for ASD itself	Most countries had policies to promote care coordination and partial care pathways
<b>Community-based services and support</b>	Shortage of respite care and places in special schools, but autism-specific community support available	Respite care available, but general lack of funding
<b>Family professional partnership</b>		
<b>Transition into adulthood</b>		Adult services lacking
<b>Quality Assurance</b>		
<b>Discussion, debate and controversy</b>	Controversy around the causes and (over)diagnosis of ASD. Lack of evidence for some Government-funded treatments.	Some improvements in public and political understanding of ASD.

Figure 15.2: Summary of divergence of European and Australian findings for ASD

A more detailed matrix of findings can be found in *Appendix 7*.

## 16. Convergence on European and Australian findings on ADHD

There was a large amount of convergence between the European and Australian findings from the *Standards for Systems of Care for CYSCHN* and the *European Survey of Change*. The key areas of convergence were:

Convergence	Barriers	Facilitators
<b>Screening, assessment and referral</b>	Few national policies and procedures	
<b>Access to care</b>	Lack of funding and available staff, fees, long waiting lists, time constraints of practitioners	Parents' involvement, multidisciplinary solutions and universal health cover
<b>Care coordination</b>	Insufficient policies or procedures promoting care coordination for ADHD	Parental involvement
<b>Community-based services and support</b>	Lack of funding in general, shortage of respite care	
<b>Family professional partnership</b>	Family can access psychosocial supports but out of pocket costs, waitlists, shortage of specialists	
<b>Transition into adulthood</b>	Lack of services and specialists to transition to. No consistent policies or procedures	
<b>Quality Assurance</b>	No national policies or universal procedures, data rarely collected	
<b>Discussion, debate and controversy</b>	Conflict between biological and social models of origins of ADHD, controversy over medicalisation of ADHD, lack of recognition about the challenges of living with ADHD	

Figure 16.1: Summary of convergence of European and Australian findings for ADHD

The key areas of difference were:

Divergence	Australia	Europe
<b>Screening, assessment and referral</b>	Children not prescribed medication may not receive ongoing screening Shift in parent desire from an ADHD diagnosis to ASD (funding-related)	In most countries, screening and preventative care is performed by individual professionals not working in a team
<b>Access to care</b>	Child seen by CAMHS only if significant comorbidities, with no treatment for ADHD itself NDIS is potentially a barrier to integration (focus on permanent impairment) The Better Access scheme has increased	More regulations about healthcare than social care

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	ability to access government-funded psychology services	
<b>Care coordination</b>	Disintegration of school support services and lack of recognition of need for integrated care including psychosocial support	Partial care pathways were available for ADHD in some countries
<b>Community-based services and support</b>	Few community-based support groups or advocacy groups Educational supports not funded for ADHD	Community-based services were key in most countries
<b>Family professional partnership</b>	Parents not involved in developing policies, procedures or review of materials	Parents were engaged in the development of policies, procedures to some extent  Family advocacy groups make recommendations to community-based services
<b>Transition into adulthood</b>	Reluctance to prescribe medication due to stigma	
<b>Quality Assurance</b>	Parents not engaged in national quality initiatives	Parents were engaged in national quality initiatives to some extent
<b>Discussion, debate and controversy</b>	Opportunity for advocacy as government willing to have some dialogue  More funding for research  Lack of specialist services focussed on lifelong persistent, chronic conditions (much more on intervention based strategies)	

Figure 16.2: Summary of divergence of European and Australian findings for ADHD

A more detailed matrix of findings can be found in *Appendix 8*.

## 17. Comparison of findings for ADHD and ASD

Key facilitators and barriers to integrated care for children with ADHD and ASD in Europe were extracted from the data and presented in a convergence matrix (see Figure 17.1), as described by O’Cathain and colleagues [34] and Farmer and colleagues [54]. The domains from the *Standards for Systems of Care for CYSCHN* and key items from the *Survey of Change* were retained to organise the findings. In this way, areas of convergence, divergence and silence between ADHD and ASD could be identified and discussed. Findings were labelled using a traffic lights system, where strongly supported facilitators were marked in green and strongly supported barriers were marked in red. Mixed findings, where the relevance of a factor was clear but it was unclear whether it was a facilitator or barrier, were marked in amber.

<i>Standards for Systems of Care Domains</i>	ADHD		ASD		
	Barrier	Facilitator	Barrier	Facilitator	
<b>Screening, assessment and referral</b>	Lack of knowledge about the condition Lack of specialists	Parental involvement	Lack of specialists	Parental involvement	<b>Partial convergence</b>
<b>Access to care</b>	Lack of knowledge about treatment and care Lack of care services		Lack of knowledge about treatment and care Lack of care services	Increased specialisation Better awareness	<b>Partial convergence</b>
<b>Care coordination</b>	Lack of coordination	Multidisciplinary teams Parental involvement	Lack of coordination	Multidisciplinary teams Parental involvement	<b>Convergence</b>
<b>Community-based services and support</b>	Lack of care services Lack of knowledge on treatment and care	Multidisciplinary teams Parental involvement	Lack of specialists	Multidisciplinary teams Parental involvement	<b>Partial convergence</b>
<b>Family professional partnership</b>	Family resources	Parental involvement		Parental advocacy	<b>Divergence</b>
<b>Transition into adulthood</b>	Lack of knowledge on treatment and care Lack of care services		Lack of knowledge on treatment and care Lack of care services	Tertiary centres for ASD	<b>Partial convergence</b>

	Structural barriers		Structural barriers		
<i>Facilitators - barriers - mixed findings</i>					

Figure 17.1: Convergence matrix of findings for ADHD and ASD

### 17.1. Screening, assessment and referral

There was partial agreement of key findings emerging from the ASD and ADHD data. Parental involvement was identified by Country Agents as a facilitator of integration during screening, assessment and referral for children with ASD. Parents of these children often initiated the assessment process, played a role in securing referrals and coordinated the elements required for diagnosis. The centrality of parents in the screening and assessment phase of care for children suspected of having ADHD was present but to a lesser extent than for ASD. The business process models highlighted that screening services are generally provided by single professionals rather than multidisciplinary teams for children on the autistic spectrum and those with ADHD.

Findings suggest that a lack of specialists for assessment and referral is a barrier to integrated care when seeking a diagnosis for either ASD or ADHD. A scarcity of specialists may hinder care due to waiting times, costs, geographical location or other practical concerns, delaying the time to diagnosis, assessment by the same care provider or even to receive secondary care. For children with ADHD, this may result in the child being seen in primary care alone, and a lack of knowledge about or recognition of ADHD among primary care professionals poses further problems, especially when the referrals and next steps taken rely solely on these clinicians.

### 17.2. Access to care

Similarly, there was partial agreement between ADHD and ASD findings regarding access to care. A lack of care services was identified as a barrier to integrated care for children with both ADHD and ASD. In some countries, this took the form of a high concentration of specialist services in major cities or specialist care centres, for example, and leaving large areas without adequate coverage. In others, there was simply a shortage of appointments or places in appropriate services. In tandem with a lack of services was a lack of knowledge about how best to care for a child with ASD, and to some extent ADHD.

Integrated care for children with ASD can be facilitated by increased specialisation, implemented using gatekeepers and a stepped care approach, and better awareness about ASD and the care needs presented by the condition. Facilitators for integrated care for children with ADHD did not emerge with regards to access to care.

### 17.3. Care coordination

For both children with ASD and children with ADHD, a lack of care coordination was a serious barrier to integrated care, resulting in delayed, fragmented or incomplete care. It was noticeable that policies and procedures regulating care coordination and care pathways were more widely available regarding ASD than ADHD, where care coordination was less developed.

Multidisciplinary teams facilitated integrated care through improved communication and access to appropriate specialists. Such teams were often accompanied by a personalised care plan outlining roles and responsibilities of each clinician. Parental involvement in care coordination was also identified as a facilitator for integration, in some cases playing the role of coordinator themselves. This was central for both children with ADHD and children with ASD.

#### **17.4. Community-based services and support**

Cross-sectoral multidisciplinary teams incorporating community-based services were identified as key facilitators of integrated care for both ADHD and ASD. Parental involvement with community-based supports and services contributes to integrated care, particularly through parents' associations, which provide coaching, networking and supports in the community. Parents' association were also involved in advocacy, to a greater extent for ASD than for ADHD.

The barriers to integrated care relating to community-based care were different for children with ASD and children with ADHD. A lack of care services in the community was much more of a problem for children with ADHD than ASD. Care integration is hindered by insufficient knowledge about how to care for a child with ADHD's needs at the community level, often due to a lack of professionals with appropriate expertise, as well as poor knowledge about ADHD among primary care professionals. For ASD, there was sufficient knowledge regarding the care required by community-based services, but a lack of specialists was the main barrier.

#### **17.5. Family professional partnership**

The main facilitators and barriers relating to the family professional partnership diverged, as the family-professional partnership was more formalised for ASD than for ADHD. The parents of children with ASD participated in the development of policies, procedures and national quality initiatives in more countries than parents of children with ADHD. Parental involvement in coordination and other everyday activities was stressed in the responses about ADHD, while parental advocacy was emphasised in the data about ASD to a much greater extent.

The resources of the family were described as a potential barrier for the care of children with ADHD, as a number of services often had a cost attached, bringing concerns about equity of access into focus.

#### **17.6. Transition into adulthood**

A number of barriers were identified that hinder the integration of care with respect to transitioning to adult care. For both ADHD and ASD, there is insufficient knowledge among relevant stakeholders about how to meet the complex care needs for adolescents transitioning to adulthood. In addition, children with ADHD transitioning to adult care often face the misconception among care providers that ADHD will disappear in adulthood, and as a result, appropriate transition to adulthood and indeed, care for adult ADHD in general, is not available. A shortage of services for ASD in adulthood is also a barrier to adequate care, but to a lesser extent than for adult ADHD. There are also structural barriers including a scarcity of policies and procedures managing the transition to adult care and a strict delineation between services based on age alone. Tertiary centres for ASD care may facilitate smooth transition to adult care

due to access to a range of services and clinicians in a single location. However, these specialist centres were not described in the data regarding ADHD.

### 17.7. Key findings from the business process models

The business process models portrayed some key processes involved in the complex care of children with ADHD and ASD, highlighting the actors and level of collaboration involved. This analysis highlights that when professional teams are in place collaboration between actors shows no major differences between ASD and ADHD.

- Screening services, as well as plan development and implementation, are generally provided by single professionals rather than a multidisciplinary team for children on the autistic spectrum as well as those with ADHD.
- There is a higher level of collaboration in the provision of health screening services for ASD (half of the respondent countries) than for ADHD (a third of the countries). Moreover, in the majority of the countries (two-thirds), social screening is provided by single professionals for ASD and ADHD.
- A lower degree of collaboration is present for the development and implementation of the personalized plan, as these activities are performed by single professionals in the majority of the countries. However, a slightly higher presence of teams is available in the development of a personalised plan for ASD compared to the one for ADHD.
- In a minority of countries, social aspects of child’s care are implemented by a collaboration that includes social workers and school care professionals.

### 17.8. Summary

The main barriers at the interface of primary care for children with ASD and ADHD were a lack of specialists, a lack of knowledge about treatment and care, and a lack of care services. This suggests that major investment in service provision and specialist training may be required to meet the shortfall.

The main facilitators were parental involvement and multidisciplinary teams, suggesting that a reorganisation of specialists and increased engagement and support for parents may be beneficial.

<i>Barriers</i>	<i>Facilitators</i>
<i>Lack of care services</i>	Better awareness
<i>Lack of coordination</i>	Increased specialisation
<i>Lack of knowledge about the condition</i>	Multidisciplinary teams
<i>Lack of knowledge about treatment and care</i>	Parental advocacy
<i>Lack of specialists</i>	Parental involvement
<i>Structural barriers</i>	Tertiary centres
<i>Family resources</i>	

Figure 17.2: Summary of main barriers and facilitators

## 18. Needs and future visions for care of children with complex mental health conditions

This report contains insights from multiple strands of the MOCHA project, namely DIPEX patient experiences, a business process model approach and the Australian study. The multi-faceted nature of complex mental health conditions requires that a broad range of methodologies be employed to triangulate findings and that a variety of perspectives from multiple spheres be taken to grasp the full picture. Based on an analysis of these pieces of research, a discussion of the needs and future visions for care of children with ASD and ADHD, and the potential to generalise to children with other complex mental health conditions, is presented below. The methodological approach used and its limitations is discussed in Chapter 5.

The recommendations resulting from this study fall into two main domains relating firstly, to coordination within multidisciplinary structures, and secondly, to the attitudes and awareness within the wider societal context. The public and political context provides the framework within which organisations, practitioners and parents must operate when providing and supporting services, communicating with other actors and advocating for their child's care. Parental involvement, multidisciplinary expertise and access to appropriate care were identified as interrelated factors facilitating and being facilitated by coordination.

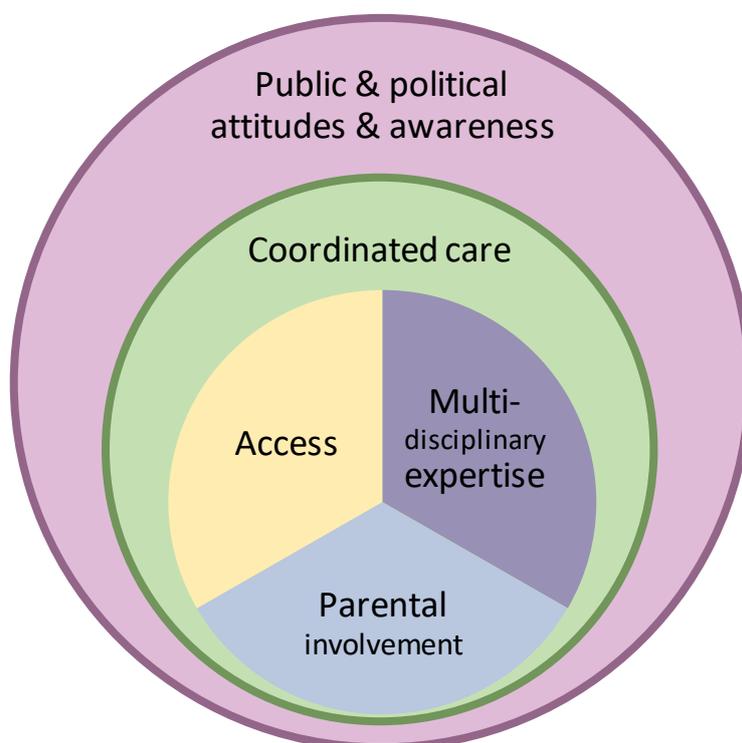


Figure 18.1: Model of key themes influencing care for children with enduring mental health needs at the primary care interface

## **18.1. Coordinated care within multidisciplinary clusters**

Findings from across the MOCHA project relating to mental health suggest that easily accessible coordinated clusters of multidisciplinary professional knowledge may be beneficial for integrating care for children with ADHD and ASD. The business process models portrayed the wide variety of structures, configurations and types of teams caring for such children that currently exist in the respondent countries. At present, the organisational integration of services is challenged by a lack of knowledge regarding care needs of both conditions, and for ADHD, knowledge of the condition itself, and an unsystematic use of existing knowledge in different sectors. Without organisational integration, the multiple transitions between care providers and at different life stages create real challenges for children with ASD and their families. A lack of collaboration between existing actors and service systems results in a fragmented care continuum, causing care to be inadequate, incomplete, or inaccessible. Further, there is a high prevalence of comorbidity among children and adolescents with mental health difficulties, both in terms of other psychiatric disorders, but also physical health and social disparities [55].

Although implementing successful integration is challenging, it is instrumental in achieving safe and efficient care in practice. Integration could be applied at the micro-level (within one provider), meso-level (between several services) and macro-level (between ministries) and could involve both horizontal (between health and social services via multi-disciplinary teams, for instance) and vertical integration (across primary, community, hospital and tertiary care services). Thus, applying the principle of integration could take the form of clusters of specialists to fully meet the ongoing social, psychological, physical and pedagogical needs for children and adolescents with enduring mental health disorders.

### **18.1.1. Comprehensive formalised coordination**

Multidisciplinary teams benefit from fewer transitions, each of which represents a risk to the continuity of care. Improved communication within a multidisciplinary team facilitates timely, safe and effective care and removes barriers such as varying care foci across sectors and an insufficient knowledge base, thus avoiding the pitfalls of being treated by multiple clinicians in discrete organisations. While national legislation and regulation were described as facilitators for care coordination, some respondents were concerned that bureaucratisation could risk distracting practitioners away from the care they seek to provide.

The research demonstrated a reliance on parents to coordinate their child's care, persist in accessing multiple services and in some cases, initiate assessment and pay for care or supports, as well as provide everyday parenting and special care for their child's condition. The issues with care delivery as it stands can result in overburdening parents, who may become overwhelmed with the challenge of accessing care for their child. This points to a need for coordinated care, optimally within a multidisciplinary team, so that coordination does not fall to the parents alone. This multidisciplinary coordination should include social care, including psychoeducation and practical supports for family members.

Although explicit CAMH policies can improve the quality and accessibility of services and promote the mental health of all children and adolescents within a country, CAMH policies and procedures tend to lack clear definitions to ensure that these mental healthcare needs are met

[56]. Currently, care needs are often well-defined for specific diagnoses, leading to diagnosis-specific interventions, for diagnoses such as ADHD and ASD, for example, rather than a holistic treatment of the individual's mental health needs. This approach is problematic due to the high frequency of comorbidity, which may not be accounted for in a diagnosis-focused approach, and therein lies the potential to exclude those most in need from intervention.

Continuity over time is also critical. Impairment related to ASD and ADHD can appear differently at various stages across the lifespan [57], pointing to the need for an individual care plan with regular follow-ups and revisions as needed. Further, transitions between, for example, different healthcare units or from child to adult services, have a high degree of complexity regarding both specialization and organized care pathways [58, 59, 60].

In most European countries, the structure of care is moving toward more specialisation in both the healthcare and social care system, increasing the need for a comprehensive coordination of services and a higher demand for specialists. The more complex the clinical task, the greater the need for coordination and subsequently, those with severe, complex and comorbid difficulties are in higher risk of experiencing fragmented treatment and care. However, the limitations of CAMH care are not only rooted in the complexities of diagnosis, treatment of comorbidity and structure of policies and procedures. Unfortunately, the gaps in the continuum of care also stem from the limited availability of services for children and young people with mental health problems and disabilities in general [6].

### **18.1.2. Parental involvement**

The role of parental involvement is key and consistent in the findings of this study as parents have several roles to play in assuring, facilitating and coordinating care. The challenge would appear to lie in achieving the right balance between empowering parents to advocate and direct the treatment of their child, successfully incorporating their knowledge and expertise regarding their child's condition, all the while being mindful not to over-burden them or make them feel overly autonomous and responsible. In addition to the challenges of being parents to a child with mental health condition with particular needs, they are also parents in a family. In this study, the voice of siblings was not found to play a key role in the coordination of care at the meso-level, but siblings may very well play a key role in how the parents are able to engage in care coordination for the child with a mental health condition. Thus, parents' voices regarding the psychosocial supports required for the family must be heeded, as well as listening to their insights regarding care provision in general. Crucially, this must be done in a supportive manner where the care decisions are available, well-explained and guided by professionals with specialist knowledge across the range of care and support services. Parental involvement is key to the future advocacy of these children and therefore plays a vital role in future service design.

### **18.1.3. Access to appropriate specialists**

A strong theme that emerged was the need for appropriate specialists, which might be paediatric mental health professionals located in secondary care or clinicians with further specialisation in tertiary care. The need for social care professionals and relevant specialists in schools should not be underestimated.

However, the degree of specialization must be in balance with access, so that the specificity of the services do not present a barrier for those who need them. An example of this might be specialist care centres that provide excellent integrated care but have few places available and have a concentration of specialists in one place, leaving other regions with less coverage. Issues regarding fees and funding programmes for some services were also highlighted, which presented equity issues and barriers to access.

While services for ADHD and ASD both suffered from shortages of specialists, the gaps and bottle-necks occur at different points. A lack of specialist knowledge and secondary care practitioners present issues for children seeking assessments and referrals for an ADHD diagnosis, whereas children with ASD are faced with a shortage of services at the care stage, post-diagnosis. These could be rooted in the perceptions around the two conditions; there is still controversy over the legitimacy of ADHD as a neurodevelopmental condition, with some physicians sceptical of its biological characteristics, while ASD is a more established diagnosis. This may reveal a trajectory for services for children with ADHD, in that once ADHD is accepted and better recognised the priority for improvement will be how to better provide for care needs, rather than how to get a diagnosis.

## **18.2. Public and political awareness of and attitudes towards complex mental health conditions**

Both ASD and ADHD suffer from an amount of misunderstanding or disinterest in the public and political and professional spheres. For ASD, the tension lies over whether it belongs in the disability or mental health care systems, in that autism spectrum conditions are intellectual disabilities and not mental health issues in themselves, so should not be “treated”. However, many mental health comorbidities arise, which do need to be treated as mental health issues within appropriate care settings. A lack of integration in care provision and among professionals between mental health and disability services can lead to fragmented care and unnecessary transitions back and forth between these services.

However, the controversy for ADHD relates to whether it exists as a neurodevelopmental disorder, the issue (over-)medicalisation and the underlying causes of the condition, i.e. whether it is a parenting issue or a biological issue. While psychosocial management of the condition is critical, the quality of care will suffer if practitioners fail to recognise the developmental nature of ADHD. The related stigma around developmental and mental health conditions can be damaging for parents, who may feel blamed or overwhelmed. This is also the case for parents of children with ASD and other mental health conditions.

Fundamental to the discussion of care integration for children with complex mental health needs are issues specific to the exemplar conditions, as described, but further, these are also indicative of issues relating to mental health in principle, in contrast with physical health. The care of mental health conditions depends on the discipline and perspective of clinician, who are reliant on less demonstrable, externally-measurable symptoms, resulting in a wider variety of possible treatment paths. This may also depend on the specialisation of the clinician. Care pathways in mental health are therefore very different from physical health, where tangible symptoms can be measured.

The main themes emerging from the responses to the European survey are not surprising, and are crucial in describing the management of complex care for children with ASD and ADHD. Equally important, however, is the absence of other topics, such as the involvement of the patients in their own treatment and care. The absence of such themes may reflect that this survey focusses on the meso-level, and is less concerned with aspects and themes expected to be found closer to the clinical level. Key principles for care of children with complex mental health needs at the primary care interface

### 18.2.1. Access

- On-going screening and developmental checks should be provided regardless of detected mental health conditions
- Care provision should be accessible regardless of geographic locations of the child and family
- Care services to supporting children with mental health condition should be in place in both primary, secondary and social care
- Access to care should follow a stepped care approach
- Consideration should be given to the regional differences
- Care pathways are in place to support care delivery at the interface between services
- Consideration should be given to fee-based care which prove to be a barrier in accessing care in particular for low-income families
- Transparent referral procedures support continuity of care
- Attention to transition between services and/or in regard to lifespan changes are a part of the personal care plan of every child with mental health conditions
- Political awareness and collaboration should facilitate guideline enhancing simultaneous access to different services

### 18.2.2. Parental involvement

- Parents should be included as partners in their child's care
- The parents should receive information about their child's care in a linguistic appropriate manner
- The parents should receive information about their child's care in a culturally appropriate manner
- The families to children with mental health conditions are provided with psychosocial support
- The parents and parent advocacy groups are invited to participate in the development of policies and procedures affecting their child.
- Parents should be provided with an overview of their child's caregivers
- Parents should be presented with an overview of possible accessible care services and those' interfaces
- Parents should have a voice in quality assurance at regional and national level

### 18.2.3. Multidisciplinary teams

- The need level of knowledge on mental health conditions should be ensured both in regard to the health care and the social care aspects
- Responsibilities between caregivers should be communicated and coordinated
- A personalized care plan should be accessible for all involved professionals across sectors and across services

Requirements and models for supporting children with complex mental health needs and the primary care interface

- The results of screening and assessment should be accessible for all caregivers
- Professionals across sectors should be included as partners in regional and national quality assurance
- A standard for the multidisciplinary approach in care provision for children with mental health conditions could heighten coordination between health care and social care
- Primary care providers have specialised training in the care of children with mental health conditions
- Social care providers have specialised training in the care of children with mental health conditions
- The ranges of care services have training in how to coordinate care
- School health systems have specialised training and are able to support and educate the child with mental health conditions

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## Appendices

### Appendix 1: Acknowledgment of Contributions

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The expertise of relevant professionals was sought and those who provided their details are acknowledged with thanks below. Some contributors preferred to remain anonymous.

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Razem ADHD Przeciwdziałamy

[www.adhd-online.pl](http://www.adhd-online.pl); [www.pomocdlarodzicow.pl](http://www.pomocdlarodzicow.pl)

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## Appendix 2: Questionnaire Response Rate

Country	ADHD	Autism
Austria	✓	✓
Belgium	✓	✓*
Bulgaria	***	✓
Croatia	✓	✓
Cyprus	✓	✓
Czech Republic	✓	✓
Denmark	✓	✓
Estonia	✓	✓
Finland	✓	✓
France	✓*	✓
Germany	✓	✓
Greece	✓*	✓*
Hungary	✓	✓
Iceland	✓	✓*
Ireland	✓	✓
Italy	✓	✓
Latvia	✓	✓
Lithuania	✓*	✓*
Luxembourg		
Malta	✓	✓
The Netherlands		✓*
Norway	✓	✓
Poland	✓*	✓
Portugal	✓	✓
Romania	✓	✓
Slovakia		
Slovenia	***	***
Spain	✓	✓
Sweden	✓*	** *
United Kingdom	✓	✓
<b>Total</b>	<b>25</b>	<b>26</b>

*Grey boxes means that response was included in report.*

*\* Clarifications were sought but not received in time.*

*\*\*Text commentary only was received.*

*\*\*\* Response not included in report due to deadline exceedance, but response was returned, and response supports report findings.*

## Appendix 3: ASD Questionnaire (Europe)

### WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care

#### Task 2: Complex Care Survey (enduring mental health issues)

Dear Colleague,

The research team on Task 2 of WP2 MOCHA are to provide a reliable and comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute/community/primary interface. This is to generate an evidence base of clear and accessible information concerning current provision of care. We are seeking your feedback on a number of specific scenarios where a child has an enduring and complex health condition. In this case, we are looking at **Autism**.

To answer these questions, the WP team suggest that you should seek to find **someone who understands the medical complexity outlined in the scenario**. This person could be a professional placed in the mental health service or social service, advocacy group, diagnose specific actions group, and / or primary care personnel. In addition national leads from department of health and /or department of education may be relevant.

To answer the questions about family engagement, you should ideally seek the views of a patient advocacy group. Please answer as many questions as you can, giving examples or elaborating if you would like. Included with these questionnaires is a glossary of terms.

The survey consists of two sections: Section 1. Systems of Care for Children with Complex Care Needs and Section 2. European Survey of Change.

At the end of the survey we ask that you to provide us with the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.

*Thank you*

#### Purpose and Context of Use

These questions are based on a validated set of measures of the complex care interface with primary care, which was developed by the Lucile Packard Foundation in the United States. We have adapted the measures for a European context and used them to develop this questionnaire. The answers will help us test how the models of primary care interact with secondary and social care in the case of a child with a complex chronic mental health condition.

Please send all answers to Denise Alexander by **November 24<sup>th</sup> 2016**.

## Case scenario – Autism

Autism or Autism Spectrum Disorder (ASD) is a set of pervasive developmental disorders, emphasised by the early onset of a triad of features: impairments in social interaction; impairments in communication; and restricted, repetitive, and stereotyped behaviour, interests, and activities (Lai, Lombardo & Baron-Cohen, 2013; World Health Organisation, 2016).

*Marcus is 2 years and 5 months old and has been newly diagnosed with autism. His development was considered normal up to the age of 15 months. He communicated with babble, held eye contact and reached motor skill milestones as expected. At 18 months Marcus's development began to stagnate, he experienced language regression and had difficulty maintaining eye contact. His parents described him as socially withdrawn, lacking interest in interacting with peers and having mannerisms with his hands. He also has a tendency to run askew, with his hands turned backwards. Currently, at diagnosis, Marcus has been assessed as having severe and pervasive difficulties in all areas of the autistic spectrum. He is not developing age appropriate expressive or receptive language. In addition, his ability for social interaction as well as functional and symbolic play is found to be deviant and not age appropriate. This is considered stereotypical of autism. Marcus's gross and fine motor skills are also affected.*

*His future health and social care should be delivered in an environment where specialists with expertise in respect to autism can provide a care plan to support his development. It is also advised that his parents receive guidance in meeting Marcus's needs in the family setting. Marcus's condition is irreversible and he is expected to receive lifelong care and treatment, aimed at preventing further regression and develop new skills. The care will be provided by a multi-disciplinary team consisting of psychiatrists, psychologists, physiotherapists, occupational therapists, special community child and youth workers, social care workers, home care nurses and respite care services.*

*There is a high degree of heterogeneity across the Autistic Spectrum. Some children with autism will experience relatively little impairment and may not require the same level of expert care as Marcus. It is expected, however, that the majority of children with autism, will require substantive care for their enduring complex care needs.*

## SECTION 1: SYSTEMS OF CARE FOR CHILDREN WITH COMPLEX HEALTH NEEDS

This section of the survey includes questions on the care of a child with autism in your country, adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (AMCHP and Lucile Packard Foundation, 2014). **Please complete each section guided by the scenario provided of Marcus and his family.**

To ensure alignment in translation across the EU countries, some of the questionnaire keywords are specified here:

**Process:** A set of interrelated activities, which transform inputs into outputs.

**Procedure/guideline:** Description of actions done in a certain way.

**Policy:** A plan or course of action, as of decision makers at macro and meso-level intend to influence and determine decisions, actions, and other matters. This is refers to a legal framework.

**A system:** A set of methods, procedures, arrangements, and activities that are carried out to form a unity or to meet a common goal.

This survey will, among other issues, deal with the integration of health and social care services. The organisation and integration of these services will vary substantially between countries. If there is a framework in your country for the integration of health and social services, please comment in the open-ended questions, as to whether the health and social needs of children with autism are adequately integrated or fragmented.

<b>1. SCREENING, ASSESSMENT, AND REFERRAL</b>			
1.1 In my country, there are policies and/or procedure(s) in place to assure that a child with autism receives <i>ongoing</i> preventative care screening and developmental checks with regard to the autism diagnosis	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	If yes, who starts this process?
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	If yes, who starts this process?
1.2 <i>If there are policies and/or procedure(s) in place to ensure that a child with autism receives ongoing preventative care screening and developmental checks with regard to the autism diagnosis,</i>  (a) please list the type of examinations provided			
(b) please name the healthcare providers that conduct these examinations (e.g. examination that screens for mental health comorbidity)			
(c) please name the social care providers that conduct these examinations (e.g. examination that screens for social health)			
1.3 In my country, there are policies and/or procedure(s) in place to document and communicate the results of such screening to	Policies Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	<i>If yes, who is in charge of the communication process?</i>

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(a) all care services (e.g. general practitioners/ primary care physicians/ paediatrician, community nurses, school, secondary care) caring for the child?	No <input type="checkbox"/>		
	Procedure(s)  Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	<i>If yes, who is in charge of the communication process?</i>
(b) to the child's parent(s) / guardian(s)?	Policies  Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	<i>If yes, who is in charge of the communication process?</i>
	Procedure(s)  Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	<i>If yes, who is in charge of the communication process?</i>
1.3 In my country, there are policies and/or procedure(s) in place to assess family competencies (e.g. knowledge and ability) that may influence on providing care for the child with autism.	Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>	<i>If yes, please list who is in charge of this assessment</i>
1.4 Have you any further comments in relation to the screening, assessment, and referral of children with autism in your country?			
<b>2. ACCESS TO CARE</b>			

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<p>2.1 There is a system in place in my country to identify</p> <p>a) all of the healthcare providers who care for children with autism.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>
<p>b) all of the social care providers who care for children with autism.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>
<p>2.2 In my country there is an agreed multi-disciplinary guideline of care for children with autism</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>
<p>2.3 Please provide a list of the statutory primary and secondary healthcare providers caring for children with autism in your country (For example Child and Adolescent Psychiatry or paediatric units).</p>		
<p>2.4 Please provide a list of the voluntary healthcare providers caring for children with autism in your country (For example respite services etc.)‡.</p>		
<p>2.5 Please list the professions responsible, in your country, for providing general healthcare services to children with autism in the community after treatment for an acute behavioural episode (For example general practitioner).</p>		
<p>2.6 Please list the professions responsible, in your country, for providing social care services to</p>		

‡ This list may not be exhaustive

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children with autism in the community after treatment for an acute behavioural episode (For example specialised social care workers).			
2.7 Are there policies and/or procedure(s) in your country which provide children like Marcus and his family an overview of the interface between the health care and social care system responsible for Marcus's primary and secondary care?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	
2.8 In my country there are:			
... procedures in place to ensure that children with autism are treated by the same healthcare provider / team of healthcare providers every time.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	
... there are procedures in place to ensure that children with autism are treated by the same social care provider / team of social care providers every time.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	
... a child with autism can access primary care regardless of care provided in secondary care and vice versa.	Yes <input type="checkbox"/> No <input type="checkbox"/>		
... there are policies and / or procedures in place to facilitate or hinder children with autism access to simultaneous care in both primary and secondary care.	Yes <input type="checkbox"/> No <input type="checkbox"/>	Facilitators	Barriers
... The transportation to care service for children with autism (e.g. access to special school, health assessment, etc.) in my country is provided by:	(a) the child's parent(s) / guardian(s) with support from the state	Yes <input type="checkbox"/> No <input type="checkbox"/>	

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	(b) the child's parent(s) / guardian(s) without support from the state	Yes <input type="checkbox"/> No <input type="checkbox"/>
	(c) the healthcare provider	Yes <input type="checkbox"/> No <input type="checkbox"/>
	(d) the social care provider	Yes <input type="checkbox"/> No <input type="checkbox"/>
2.9 In my country, there are policies and / procedure(s) in place to ensure that all information provided to families of children with autism is linguistically appropriate.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>
2.10 In my country, there are policies and / procedure(s) in place to assure that all information provided to families of children with autism is culturally appropriate.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>
	Procedure(s) Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>

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	No <input type="checkbox"/>	
2.11 Have you any further comments in relation to the accessibility of care for children with autism in your country?		
<b>3. CARE COORDINATION</b>		
3.1 In my country,		
...there are policies and/ or procedures promoting access to care coordination for the child diagnosed with autism.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
... there is a specific care pathway for children with autism	Yes <input type="checkbox"/> Partly <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) to support your answer</i>
3.2 <i>If there is a care pathway, are there policies or procedures that clearly describe each provider's role in a care pathway for children with autism</i>	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...there are procedures that ensure all care providers in a care pathway to participate in care	Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>

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coordination for the child with autism.	No <input type="checkbox"/>	
... there are procedures in place for ensuring a written personalised plan of care for children diagnosed with autism.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please list who is responsible for this?</i>
... there is specific integration procedure and/ or policy of pathways for children with autism which combine primary and secondary care	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>
<i>3.3 If there is specific integration procedure and/ or policy of pathways for children with autism which combine primary and secondary care, does this facilitate continuity?</i>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, how? If possible please link to the evidence that support your answer</i>
...the written personalised plan of care for a child with autism is developed in consultation with	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts it?</i>
(a) the child's parent(s) / guardian(s)		<i>If yes, who is in charge?</i>
(b) Other healthcare professionals	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts it?</i>
		<i>If yes, who is in charge?</i>
(c) Social care professionals	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts it?</i>
		<i>If yes, who is in charge?</i>
...the personalised written care plan for a childlike Marcus integrates the following:		
(a) developmental assessments	Yes <input type="checkbox"/>	

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	No <input type="checkbox"/>
(b) mental health comorbidity assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>
(c) physical health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(d) oral health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(e) vision health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(f) hearing assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>
(g) social health	Yes <input type="checkbox"/> No <input type="checkbox"/>
... hospital(s) that provide mental health care for children such as Marcus (both outpatient and inpatient) have a discharge planning coordinator responsible for organising the transition of a child with autism from the hospital setting to the child's home or another community based setting.	Yes <input type="checkbox"/> No <input type="checkbox"/>

3.4 Autism often is associated with a high degree of comorbidity. Can you provide information on how children with autism are cared for in your country in case of comorbidity?		
3.5 Have you any further comments in relation to the coordination of care for children with autism in in general your country?		
<b>4. COMMUNITY-BASED SERVICES AND SUPPORT</b>		
<i>4.1 In my country,</i>		
... community-based service (e.g. local initiatives or voluntary organisations) is a key component of the care approach for children with autism.	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who coordinate the community-based care with the hospital-based care
...family advocacy groups are involved in making recommendations to home and community-based services.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
... the parent(s)/guardian(s) and siblings of children with autism have access to professional psychosocial support.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who starts this process?</i>
...respite care is available for children with autism	Yes <input type="checkbox"/> No <input type="checkbox"/>	
...respite care is provided by	<b>State</b>  Yes <input type="checkbox"/>	<i>Please list the main provider for respite care in your country</i>

Requirements and models for supporting children with complex mental health needs and the primary care interface

	No <input type="checkbox"/>  <b>Voluntary sector</b>  Yes <input type="checkbox"/>  No <input type="checkbox"/>  <b>Private sector</b> Yes <input type="checkbox"/>  No <input type="checkbox"/>	
... children with autism are offered the opportunity to acquire skills and / or education according to their individual need.	Yes <input type="checkbox"/>  No <input type="checkbox"/>	
4.2 Have you any further comments in about the community based services and supports for children diagnosed with autism in your country?		
<b>5. FAMILY PROFESSIONAL PARTNERSHIP</b>		
<i>5.1 In my country parent(s) / guardian(s) of children with autism are</i>		
... invited to participate in the development of policies and procedures affecting their children.	Yes <input type="checkbox"/>  No <input type="checkbox"/>	
... included in national quality improvement	Yes <input type="checkbox"/>	

Requirements and models for supporting children with complex mental health needs and the primary care interface

initiatives for autism.	No <input type="checkbox"/>	
... involved in the review of patient and family information material on autism for the public, to ensure cultural and/or linguistic competency.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
5.2 Have you any further comments in about family professional partnerships relating to the care of children with autism in your country?		
<b>6. TRANSITION INTO ADULTHOOD</b>		
6.1 In my country, there are policies and procedure(s) in place to ensure continuity of care for adolescents with autism transitioning to adult specialists and community supports.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policies or procedures.</i>
6.2 Please list the any barriers to continuity of care for adolescents with autism transitioning to adult care services in your country.		
6.3 Have you any further comments in relation to the transition of adolescent with autism to adult care services?		
<b>7. QUALITY ASSURANCE</b>		
7.1 In my country,		
...there are quality assurance policies and/or procedures for service providers caring for children with autism	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>

Requirements and models for supporting children with complex mental health needs and the primary care interface

	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
...data is collected on the experience of care for children with autism from the perspective of:		
(a) the parent(s) / guardian(s)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertakes the collection and analysis of these data?</i>
(b) the siblings	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data?</i>
(c) primary health and social care professionals	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data?</i>
7.2 Have you any further comments about ensuring that children with autism in your country receive quality care?		

## SECTION 2: EUROPEAN SURVEY OF CHANGE

This section of the survey aims to provide a 'snapshot of the current situation of integration of care for children with complex care needs. You are asked to answer a number of questions to help us gain an understanding of current issues and debates on the issues of complex care for children with autism in your country.

Please answer **all** the questions as accurately as possible and make use of the space for comments to clarify your information and to describe distinct characteristics of services/health organisations in your country.

### 1. QUESTIONS ON THE CURRENT STATE OF DEVELOPMENT OF SERVICES FOR CHILDREN DIAGNOSED WITH AUTISM

1.1 Please list the three most significant changes that have taken place in the integration of care services for children diagnosed with autism in your country in the last five years?

(i)

(ii)

(iii)

1.2 How would you evaluate the overall progress in the integration of care services for children with autism in your country in the last five years? Please indicate with an 'x' the one statement that best describes this progress from the three options given below. Since January 2010 the integration of care for children with autism.

(i) has improved

(ii) has remained very much the same

(iii) has got worse

1.3 Please list in order of importance the three main **barriers** to the integration of care services for children with autism in your country at the present time:

(i)

(ii)

(iii)

1.4 Please list in order of importance the three main **opportunities** to the integration of care services for children with autism in your country at the present time:

(i)

(ii)

(iii)

## 2. QUESTIONS ON POLICY AND SOCIO-CULTURAL ISSUES

2.1 What strategies have been used to improve political awareness and government recognition of the need for integration of care services for children with autism in your country in the last five years?

2.2 Have there been any special funding initiatives for this group by government, private/voluntary care organisations, Non-Governmental Organisations, Organizzazione Non lucrativa di Utilità Sociale (ONUS), or donors in the last five years?

2.3 Has there been any involvement between your country and the European Union in relation to initiatives on managing the integration of care of children with autism in the last five years?

2.4 Has there been any major public discussion, debate or controversy about the needs of children with autism in your country in the last five years?

**Please provide the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.**

## **Appendix 4: ADHD Questionnaire (Europe)**

### **WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care**

#### **Task 2: Complex Care Survey (enduring mental health issues)**

Dear Colleague,

The research team on Task 2 of WP2 MOCHA are to provide a reliable and comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute/community/primary interface. This is to generate an evidence base of clear and accessible information concerning current provision of care. We are seeking your feedback on a number of specific scenarios where a child has an enduring and complex health condition. In this case, we are looking at **Attention Deficit Hyperactivity Disorder (ADHD)**.

To answer these questions, the task team suggest that you should seek to find **someone who understands the complexity outlined in the scenario**. This person could be a professional placed in the mental health service or social service, advocacy group, diagnosis specific actions group, and / or primary care personnel. In addition national leads from a Department of Health and /or a Department of Education may be relevant.

To answer the questions about family engagement, you should ideally seek the views of a patient advocacy group. Please answer as many questions as you can, giving examples or elaborating if you would like. Included with these questionnaires is a glossary of terms.

The survey consists of two sections: Section 1. Systems of Care for Children with Complex Care Needs and Section 2. European Survey of Change.

At the end of the survey we ask that you to provide us with the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.

*Thank you*

#### **Purpose and Context of Use**

These questions are based on a validated set of measures of the complex care interface with primary care, which was developed by the Lucile Packard Foundation in the United States. We have adapted the measures for a European context and used them to develop this questionnaire. The answers will help us test how the models of primary care interact with secondary and social care in the case of a child with a complex chronic mental health condition.

Please send all answers to Denise Alexander by **November 24<sup>th</sup> 2016**.

## Case scenario – Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) is a childhood-onset neurodevelopmental disorder characterised by developmentally inappropriate and impairing inattention, motor hyperactivity, and impulsivity, with difficulties often continuing into adulthood (Thapar & Cooper, 2015)

*Pedro is a 12 year old boy. Since his parents divorced two years ago he now lives with his mother and her new husband, his 14 year old sister and his two older stepsisters. He was diagnosed with ADHD at the age of 8. Prior to Pedro's diagnosis he found it hard to concentrate in school and was restless and disruptive in class. At home he also displayed challenging behavior and had sleep issues. Currently he is being treated with medication and his family has received instructions on how best to support him by introducing structured daily routines. His sleeping issues are being treated with a special weighted blanket and a sleep hormone with good effect. Pedro's medical treatment is followed up on a regular basis by a specialist. He attends the local mainstream primary school. Since starting treatment Pedro's concentration in school has increased but he still struggles with his school work. In order to minimise Pedro's specific academic challenges, he has been given his own workstation in the classroom and his teachers have been advised to structure his school day. In addition, his teacher has been asked to ensure that before starting a new task Pedro is listening and understands the task. These accommodations should assist Pedro's concentration and enable him to better complete his school work.*

*Pedro's ADHD is a lifelong condition, but with the right treatment his difficulties can be minimised. His future care is predicted to consist of mental health care provided by a range of specialists (doctors and nurses to follow up medication), social care and academic interventions and accommodations.*

## SECTION 1: SYSTEMS OF CARE FOR CHILDREN WITH COMPLEX HEALTH NEEDS

This section of the survey includes questions on the care of a child with ADHD in your country, adapted from the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (AMCHP and Lucile Packard Foundation, 2014). Please complete each section guided by the scenario provided of Pedro and his family.

To ensure alignment in translation across the EU countries, some of the questionnaire keywords are specified here:

**Process:** A set of interrelated activities, which transform inputs into outputs.

**Procedure/guideline:** Description of actions done in a certain way.

**Policy:** A plan or course of action of decision makers at macro and meso-level to influence and determine decisions, actions, and other matters. This refers to a legal framework.

**A system:** A set of methods, procedures, arrangements, and activities that are carried out to form a unity or to meet a common goal.

This survey will, among other issues, deal with the integration of health and social care services. The organisation and integration of these services will vary substantially between countries. If there is a framework in your country for the integration of health and social services, please comment in the open-ended questions, as to whether the health and social needs of children with ADHD are adequately integrated or fragmented.

1. SCREENING, ASSESSMENT, AND REFERRAL			
1.1 In my country, there are policies and/or procedure(s) in place to assure that a child such as Pedro receives <i>ongoing</i> preventative care screening and developmental checks with regard to their ADHD diagnosis.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies.</i>	If yes, who starts this process?
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>	If yes, who starts this process?
1.2 Are there are policies and/or procedure(s) in place to ensure that a child like Pedro receives ongoing preventative care, screening and developmental checks. If there is variation from a child without ADHD please state.  (d) please list the type of examinations provided			
(e) Who, in your country, provides screening / ascertainment of mental health comorbidity for children like Pedro			

<p>(f) Who, in your country would provide screening/ascertainment for social needs?</p>			
<p>1.3 In my country, there are policies and/or procedure(s) in place to document and communicate the results of such screening to</p> <p>(c) all care services (e.g. general practitioners/ primary care physicians/ paediatrician, community nurses, school, secondary care) caring for the child?</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
	<p>Procedure(s)</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
<p>(d) the child's parent(s) / guardian(s)?</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>
	<p>Procedure(s)</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>	<p><i>If yes, who is in charge of the communication process?</i></p>

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<p>1.4 In my country, there are policies and/or procedure(s) in place to assess family capacities (e.g. knowledge and ability) that may influence providing care for the child with ADHD.</p>	<p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p>	<p>If yes, please provide reference(s) for the policy or policies</p>	<p>If yes, please list who is in charge of this assessment</p>
<p>1.5 Have you any further comments in relation to the screening, assessment, and /or referral of children with ADHD in your country?</p>			
<p><b>2. ACCESS TO CARE</b></p>			
<p>2.1 There is a system in place in my country to identify</p> <p>c) all of the healthcare providers who care for children with ADHD.</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>	
<p>d) all of the social care providers who care for children with ADHD.</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>	
<p>2.2 In my country there is an agreed multi-disciplinary guideline of care for children with ADHD</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, who is in charge of this?</i></p>	
<p>2.3 In my country formal training on how to best care for children with ADHD is provided to the</p>	<p>Yes <input type="checkbox"/></p>	<p><i>If yes, which type of care are the parent(s) / guardian(s) to provide?</i></p>	

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parent(s) / guardian(s).	No <input type="checkbox"/>	
<p>2.4 <i>If parent(s) / guardian(s) receive formal training with regard to the care of children with ADHD</i></p> <p>are there policies and/or procedures in place to ensure that they have the capacity (e.g. knowledge and ability) to incorporate this into their child's daily routine</p>	<p>Policies</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>
	<p>Procedure(s)</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>
2.5 Please provide a list of the statutory primary and secondary healthcare providers caring for children with ADHD in your country (For example Child and Adolescent Psychiatry or paediatric units).		
2.6 Please provide a list of the voluntary healthcare providers caring for children with ADHD in your country (For example respite services etc.) §.		
2.7 Please list the professions responsible, in your country, for providing general healthcare services to		

§ This list may not be exhaustive

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<p>children with ADHD in the community after treatment for an acute behavioural episode (For example general practitioner).</p>		
<p>2.8 Please list the professions responsible, in your country, for providing social care services to children with ADHD in the community after treatment for an acute behavioural episode (For example specialised social care workers).</p>		
<p>2.9 Are there policies and/or procedure(s) in your country, which provide children like Pedro and his family an overview of the interface between the health care and social care system responsible for Pedro's primary and secondary care?</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>
<p>2.10 In my country ...</p>		
<p>... there are procedures in place to ensure that children like Pedro are treated by the same healthcare provider / team of healthcare providers every time</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>
<p>... there are procedures in place to ensure that children with ADHD are treated by the same social care provider / team of social care providers every time.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the procedure(s)</i></p>

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<p>... a child with ADHD can access primary care regardless of care provided in secondary care and vice versa.</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) that supports your answer</i></p>	
<p>... there are policies and / or procedures in place, which facilitate or hinder children with ADHD in accessing primary and secondary care simultaneously.</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p>Facilitators</p>	<p>Barriers</p>
<p>... there is transportation to care service for children with ADHD (e.g. access to special school, health assessment, etc.) in my country is provided by</p>	<p>(e) the child's parent(s) / guardian(s) with support from the state</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
	<p>(f) the child's parent(s) / guardian(s) without support from the state</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
	<p>(g) the healthcare provider</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
	<p>(h) the social care provider</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
<p>... there are policies and / procedure(s) in place to ensure that all information provided to families of</p>	<p>Policies Yes <input type="checkbox"/></p>	<p><i>If yes, please provide reference(s) for the policy or policies.</i></p>	

children with ADHD is linguistically appropriate.	No <input type="checkbox"/>	
	Procedure(s) <i>If yes, please provide reference(s) for the procedure(s)</i>  Yes <input type="checkbox"/>  No <input type="checkbox"/>	
2.11 In my country, there are policies and / procedure(s) in place to assure that all information provided to families of children with ADHD is culturally appropriate.	Policies <i>If yes, please provide reference(s) for the policy or policies</i>  Yes <input type="checkbox"/>  No <input type="checkbox"/>	
	Procedure(s) <i>If yes, please provide reference(s) for the procedure(s)</i>  Yes <input type="checkbox"/>  No <input type="checkbox"/>	
2.12 Have you any further comments in relation to the accessibility of care for children with ADHD in your country?		
<b>3. CARE COORDINATION</b>		
3.1 In my country,		

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...there are policies and/ or procedures promoting access to care coordination for the child diagnosed with ADHD.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
... there is a specific care pathway for children with ADHD	Yes <input type="checkbox"/> Partly <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) to support your answer</i>
<i>3.2 If there is a care pathway for children with ADHD are there policies or procedures that clearly describe each provider's role in a care pathway for children with ADHD</i>	Yes <input type="checkbox"/> No <input type="checkbox"/>	
... there are procedures in place for ensuring a written personalised plan of care for children diagnosed with ADHD.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please list who is responsible for this?</i>
... there is specific integration procedure and/ or policy of pathways for children with ADHD, which	Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure(s)</i>

combines primary and secondary care	No <input type="checkbox"/>	
3.3 If there is specific integration procedure and/or policy of pathways for children with ADHD, which combine primary and secondary care, does this facilitate continuity?	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, how? If possible please link to the evidence that support your answer
...the written personalised plan of care for a child with ADHD is developed in consultation with	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who starts it?
(d) the child's parent(s) / guardian(s)		If yes, who is in charge?
(e) Other healthcare professionals	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who starts it?
		If yes, who is in charge?
(f) Social care professionals	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who starts it?
		If yes, who is in charge?
...the personalised written care plan for a child like Pedro integrates the following;	Yes <input type="checkbox"/> No <input type="checkbox"/>	
(h) developmental assessments		
(i) mental health comorbidity assessments	Yes <input type="checkbox"/>	

	No <input type="checkbox"/>
(j) physical health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(k) oral health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(l) vision health	Yes <input type="checkbox"/> No <input type="checkbox"/>
(m) hearing assessments	Yes <input type="checkbox"/> No <input type="checkbox"/>
(n) social health	Yes <input type="checkbox"/> No <input type="checkbox"/>
... hospital(s) that provide mental health care for children such as Pedro (both outpatient and inpatient) have a discharge planning coordinator responsible for organising the transition of a child with ADHD from the hospital setting to the child's	Yes <input type="checkbox"/> No <input type="checkbox"/>

home or another community based setting.		
3.4 ADHD often is associated with a high degree of comorbidity. Can you provide information on how children with ADHD are cared for in your country in case of comorbidity?		
3.5 Have you any further comments in relation to the coordination of care for children with ADHD in in general your country?		
<b>4. COMMUNITY-BASED SERVICES AND SUPPORT</b>		
4.1 In my country,		
... community-based services (e.g. local initiatives or voluntary organisations) are a key component of the care provided to children like Pedro.	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who coordinate the community-based care with the hospital-based care
...family advocacy groups are involved in making recommendations to home and community-based services for children with ADHD.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
... the parent(s)/guardian(s) and siblings of children with ADHD have access to professional psychosocial support.	Yes <input type="checkbox"/> No <input type="checkbox"/>	If yes, who starts this process?

<p>...respite care is available for the parent(s) / guardian(s) children with ADHD</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	
<p>4.2 If respite care is available, is it provided by</p>	<p><b>State</b></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p><b>Voluntary sector</b></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p><b>Private sector</b> Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	<p><i>Please list the main provider for respite care in your country</i></p>
<p>... children with ADHD are offered individually tailored educational and / or training interventions or accommodations in response to their specific requirements.</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>	

4.3 Have you any further comments in about the community based services and supports for children diagnosed with ADHD in your country?		
<b>5. FAMILY PROFESSIONAL PARTNERSHIP</b>		
5.1 In my country parent(s) / guardian(s) of children with ADHD are		
... invited to participate in the development of policies and procedures affecting their children.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
... included in national quality improvement initiatives for ADHD.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
... involved in the review of patient and family information material on ADHD for the public, to ensure cultural and/or linguistic competency.	Yes <input type="checkbox"/> No <input type="checkbox"/>	
5.2 Have you any further comments in about family professional partnerships relating to the care of children with ADHD in your country?		
<b>6. TRANSITION INTO ADULTHOOD</b>		
6.1 In my country, there are policies and procedure(s) in place to ensure continuity of care	Yes <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policies or procedures.</i>

for adolescents with ADHD transitioning to adult specialists and community supports.	No <input type="checkbox"/>	
6.2 Please list the any barriers to continuity of care for adolescents with ADHD transitioning to adult care services in your country.		
6.3 Have you any further comments in relation to the transition of adolescent with ADHD to adult care services?		
<b>7. QUALITY ASSURANCE</b>		
7.1 In my country,		
...there are quality assurance policies and/or procedures for service providers caring for children with ADHD.	Policies Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the policy or policies</i>
	Procedure(s) Yes <input type="checkbox"/> No <input type="checkbox"/>	<i>If yes, please provide reference(s) for the procedure or procedures</i>
...data is collected on the experience of care for	Yes <input type="checkbox"/>	<i>If yes, who undertakes the collection and analysis of these data?</i>

children with ADHD from the perspective of  (d) the parent(s) / guardian(s)	No <input type="checkbox"/>	
(e) the siblings	Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data?</i>
(f) primary health and social care professionals	Yes <input type="checkbox"/>  No <input type="checkbox"/>	<i>If yes, who undertake the collection and analysis of these data?</i>
7.2 Have you any further comments about ensuring that children with ADHD in your country receive quality care?		

## SECTION 2: EUROPEAN SURVEY OF CHANGE

This section of the survey aims to provide a snapshot of the current situation of integration of care for children with complex care needs. You are asked to answer a number of questions to help us gain an understanding of current issues and debates on the issues of complex care for children with ADHD in your country.

Please answer **all** the questions as accurately as possible and make use of the space for comments to clarify your information and to describe distinct characteristics of services/health organisations in your country.

### 3. QUESTIONS ON THE CURRENT STATE OF DEVELOPMENT OF SERVICES FOR CHILDREN DIAGNOSED WITH ADHD

3.1 Please list the three most significant changes that have taken place in the integration of care services for children diagnosed with ADHD in your country in the last five years?

(i)

(ii)

(iii)

3.2 How would you evaluate the overall progress in the integration of care services for children with ADHD in your country in the last five years? Please indicate with an 'x' the one statement that best describes this progress from the three options given below. Since January 2010 the integration of care for children with ADHD.

(iv) has improved

(v) has remained very much the same

(vi) has got worse

3.3 Please list in order of importance the three main **barriers** to the integration of care services for children with ADHD in your country at the present time:

(i)

(ii)

(iii)

3.4 Please list in order of importance the three main **opportunities** to the integration of care services for children with ADHD in your country at the present time:

(i)

(ii)

(iii)

#### 4. QUESTIONS ON POLICY AND SOCIO-CULTURAL ISSUES

4.1 What strategies have been used to improve political awareness and government recognition of the need for integration of care services for children with ADHD in your country in the last five years?

4.2 Have there been any special funding initiatives for this group by government, private/voluntary care organisations, Non-Governmental Organisations, Organizzazione Non lucrativa di Utilità Sociale (ONUS), or donors in the last five years?

4.3 Has there been any involvement between your country and the European Union in relation to initiatives on managing the integration of care of children with ADHD in the last five years?

4.4 Has there been any major public discussion, debate or controversy about the needs of children with ADHD in your country in the last five years?

**Please provide the names and contact details of all those who provided feedback, so that we may acknowledge their contribution in our final report.**

**Appendix 5: Summary of business process model results for ASD**

	Screening		Personalised plan	
	Health	Social	Develop	Implement
Professional collaboration	Denmark, Estonia, Finland, Ireland, Norway, UK	Denmark, Estonia, Finland, Ireland, Norway, UK	Denmark, Finland, Ireland, Norway, UK	Denmark, Finland, Ireland, Norway, UK
Mixed team (PC + SoC or SC + SoC)	Belgium, Germany, Greece, Iceland	Belgium, Germany, Greece, Iceland	Belgium, Estonia, France, Greece	Belgium, Estonia, France, Greece
Secondary and Primary Care team	Czech R.		Czech R.	Czech R.
Care team (SC or PC or SoC)	Bulgaria		Bulgaria, Germany	Bulgaria, Germany
Individual professionals	Austria, Croatia, France, Hungary, Italy, Latvia, Lithuania, Malta, Netherlands, Poland, Portugal, Romania, Spain	Austria, Bulgaria, Croatia, Czech R., France, Hungary, Latvia, Lithuania, Malta, Poland, Portugal, Romania, Spain	Iceland, Italy, Lithuania, Malta, Poland, Portugal, Romania, Spain	Iceland, Italy, Lithuania, Malta, Poland, Portugal, Romania, Spain
No response	Cyprus	Cyprus, Italy, Netherlands	Austria, Croatia, Cyprus, Hungary, Latvia, Netherlands	Austria, Croatia, Cyprus, Hungary, Latvia, Netherlands
Questionnaire not sent back	Luxembourg, Slovakia, Slovenia, Sweden			

**Appendix 6: Summary of business process model results for ADHD**

	Screening		Personalised plan	
	Health	Social	Develop	Implement
Professional collaboration	Denmark, Estonia, Finland, Ireland, Norway, UK,	Denmark, Estonia, Finland, Ireland, Norway, UK,	Denmark, Finland, Ireland, Norway, UK	Denmark, Finland, Ireland, Norway, UK
Mixed team (PC + SoC or SC + SoC)	Belgium, Greece	Belgium, Greece	Estonia, Greece	Estonia, Greece
Secondary and Primary Care team	Czech R.			
Care team (SC or PC or SoC)			Germany	Germany
Individual professionals	Croatia, Cyprus, Germany, Hungary, Iceland, Italy, Latvia, Lithuania, Malta, Poland, Portugal, Romania, Spain	Croatia, Cyprus, Czech R., Germany, Hungary, Iceland, Italy, Latvia, Lithuania, Malta, Poland, Portugal, Romania, Spain	Croatia, Cyprus, Czech R., Hungary, Iceland, Italy, Lithuania, Malta, Poland, Portugal, Romania,	Croatia, Cyprus, Czech R., Hungary, Iceland, Italy, Lithuania, Malta, Poland, Portugal, Romania
No response	Austria, France, Sweden	Austria, France, Sweden	Austria, Belgium, France, Latvia, Spain, Sweden	Austria, Belgium, France, Latvia, Spain, Sweden
Questionnaire not sent back	Bulgaria, Luxembourg, Netherlands, Slovakia, Slovenia			

## Appendix 7: Convergence of European and Australian findings for ASD

Facilitators with the strongest support were marked in green, and barriers with the strongest support were marked in red. Facilitators and barriers deemed less important or with less strong evidence were marked in grey.

	Australia		Europe		Convergence
	Barrier	Facilitator	Barrier	Facilitator	
<b>Screening, assessment and referral</b>	<p><b>National policies and procedures focus on diagnosis</b></p> <p><b>No national policies to ensure ongoing preventative care, screening and checks.</b></p> <p>No policies to document and communicate these screening results to parents or other healthcare providers although majority agreed parents would be informed. Communication between other healthcare providers likely to depend on relationships between clinicians</p>		<p>Main focus of national policies and procedures is on diagnosis</p> <p>Nearly half of the EU countries have national policies and procedures ensuring preventative care screening and developmental checks</p> <p>Half of the countries performed screening and assessment by individual professionals, the other half working in teams</p>	<p>Collaboration between professions for screening and preventative care in several countries</p>	<b>Partial convergence</b>
<b>Access to care</b>	<p><b>Lack of system to identify all healthcare and social care providers</b></p> <p><b>Lack of available staff – need for training and professional development</b></p> <p>Fee-based care</p> <p>Lack of available staff in certain areas</p>	<p><b>Universal health cover facilitates simultaneous access to primary and secondary care</b></p> <p><b>Parents' involvement</b></p> <p>No policies exist to test families' capacity, however, informal procedures mechanisms occur</p>	<p><b>Lack of system to identify all healthcare and social care providers</b></p> <p><b>Shortage of specialists and expertise</b></p> <p><b>Lack of funding</b></p> <p><b>Lack of available staff</b></p> <p>Lack of multidisciplinary guidelines</p>	<p><b>Parents' involvement</b></p> <p><b>Universal health cover facilitates simultaneous access to primary and secondary care</b></p> <p>Aim to provide care by the same professionals or multidisciplinary team</p>	<b>Convergence</b>

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	Long waiting lists in hospital outpatient clinics	<b>Multidisciplinary solutions</b> rather than policies/ procedures	Fee-based care More regulations about healthcare than social care Few policies to guarantee continuity of team, but may happen due to location, etc.		
<b>Care coordination</b>	No national policies exist promoting access to care coordination Lack of funding for proper case management by paediatricians No procedures to ensure a personalised written plan but happens as standard practice No specific care pathway exists Child seen by CAMHS only if significant comorbidities, with no treatment for ASD itself A lack of coordination of services	<b>Parents' involvement</b> <b>Parental advocacy</b> <b>Co-location of specialists and services would benefit</b> <b>Template for service integration that gets modified according to the needs of the child would benefit</b> Comorbidities managed by treating professional (e.g. paediatrician) with referral if appropriate	<b>No national legislation to coordinate between sectors</b> <b>Lack of funding</b> Lack of policies or procedures description of role of each provider (in care pathways)	<b>Parents' involvement</b> <b>Access to secondary care via primary care</b> Most countries had policies to promote care coordination The majority of the countries had a specific (partial) care pathway Most countries replied to have procedures ensuring a personalised written care plan for children diagnosed with ASD, most of them including the voice of parents, health care and social care providers	<b>Partial convergence</b>
<b>Community-based services and support</b>	Shortage of respite care Shortage in number of places in special schools	<b>Autism-specific community support</b> <b>Family advocacy groups are key components of community based supports</b>	<b>Lack of funding in general</b>	<b>Engagement of social care, school and municipality in care</b> <b>Respite care available</b> Community-based services were key in most countries	<b>Partial convergence</b>

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				Family advocacy groups make recommendations to community-based services	
<b>Family professional partnership</b>	Limited family psycho-social support due to out of pocket costs and variation in access to psychologists	Parent involvement, particularly lobbying for funding  Parents involvement in reviewing materials ensuring culturally or linguistically appropriateness	Family can access psychosocial supports but out of pocket costs, waitlists, shortage of specialists, etc.	Parents' and ASD Family advocacy groups involvement to some extent in developing policies and procedures	<b>Convergence</b>
<b>Transition into adulthood</b>	No consistent polices or procedures for the transition to adult services		Services lacking  Lack of policies for transition to adult care		<b>Convergence</b>
<b>Quality Assurance</b>	No polices exist for national quality assurance procedures  Rarely data collection on experience of care from the parents or siblings or health care professionals		No national policies or universal procedures  Data rarely collected		<b>Convergence</b>
<b>Discussion, debate and controversy</b>	Debate around children with ASD in mainstream schools and the need for autism specific schools  Controversy around the causes of autism  Lack of evidence for some of the treatments which are Government funded		School reforms towards "inclusion" in mainstream schools and need for special services for ASD	Overall awareness about ASD, both politically and among the public, has increased, but needs to be increased further.	<b>Limited convergence</b>

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	Increase in incidence reported due to increase in prevalence or over-diagnosis?  Uncertainty around the introduction of NDIS				
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## Appendix 8: Convergence of European and Australian findings for ADHD

Facilitators with the strongest support were marked in green, and barriers with the strongest support were marked in red. Facilitators and barriers deemed less important or with less strong evidence were marked in grey.

	Australia		Europe		Convergence
	Barrier	Facilitator	Barrier	Facilitator	
<b>Screening, assessment and referral</b>	<p>No national policies or universal procedures exist</p> <p>Children not prescribed medication may not receive ongoing screening</p> <p>Shift in parent desire from an ADHD diagnosis to Autism (funding-related)</p> <p>Social care screening is not routinely included</p>		<p>Few national policies and procedures about preventative care screening and developmental checks</p> <p>In most countries, screening and preventative care is performed by individual professionals not working in a team</p>	<p>Collaboration to some extent for screening and preventative care in some countries</p>	<b>Limited convergence</b>
<b>Access to care</b>	<p>Child seen by CAMHS only if significant comorbidities, with no treatment for ADHD itself</p> <p>Lack of funding in child psychiatry</p> <p>Lack of available staff – need training and professional development</p> <p>NDIS is potentially a barrier to integration (focus on permanent impairment)</p> <p>Cost of services to parents</p> <p>Long waiting lists, time</p>	<p>Parents' involvement (and training for parents)</p> <p>Multidisciplinary solutions rather than policies/procedures</p> <p>Universal health cover facilitates simultaneous access to primary and secondary care</p> <p>Long acting medications which has made it easier for children at school</p> <p>The Better Access scheme</p>	<p>Shortage of specialists and expertise</p> <p>Lack of funding</p> <p>Lack of available staff</p> <p>Fees, long waiting lists, time constraints</p> <p>More regulations about healthcare than social care</p> <p>Few policies to guarantee continuity of team, but may happen due to location, etc.</p>	<p>Parents' involvement (and training for parents)</p> <p>Care provided by the same multidisciplinary team</p> <p>Universal health cover facilitates simultaneous access to primary and secondary care</p>	<b>Partial convergence</b>

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	<p>constraints</p> <p>No national multidisciplinary guidelines but use other guidelines</p> <p>No policies to guarantee continuity of team, but may happen due to location, etc.</p>	<p>has increased ability to access government-funded psychology services</p>			
<b>Care coordination</b>	<p>No policies or procedures promoting care coordination for ADHD</p> <p>No care pathway for ADHD</p> <p>No procedures to ensure a personalised written plan but happens as standard practice</p> <p>Disintegration of school support services and lack of recognition of need for integrated care including psychosocial support</p> <p>Lack of funding for proper case management by paediatricians</p> <p>Need improved co-ordination across health (Medicare), disability (NDIS) and education sectors</p>	<p>Parents' involvement</p> <p>Parental advocacy</p> <p>Co-location of specialists and services would benefit</p> <p>Template for service integration that gets modified according to the needs of the child would benefit</p> <p>Comorbidities managed by treating professional (e.g. paediatrician) with referral if appropriate</p>	<p><b>Insufficient national legislation to coordinate between sectors</b></p> <p>In most countries, the development and implementation of the plan is performed by professionals individually, not a team</p> <p>Social care and educational professionals collaborate in only a minority of countries</p> <p>Partial care pathways were available for ADHD in some countries</p> <p>No procedures to ensure a personalised written plan but commonly happens</p>	<p>Parents' involvement</p> <p>Access to secondary care for ADHD and comorbidities via primary care</p>	<b>Partial convergence</b>
<b>Community-based services and support</b>	<p><b>Lack of funding in general</b></p> <p><b>Few community-based support groups</b> or advocacy groups</p> <p><b>Educational supports not</b></p>		<p><b>Lack of funding in general</b></p> <p>Respite care was available to some extent</p>	<p>Engagement of social care, school and municipality in care</p> <p>Community-based services</p>	<b>Partial convergence</b>

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	<p><b>funded for ADHD</b></p> <p>Shortage of respite care</p>			<p>were key in most countries</p>	
<p><b>Family professional partnership</b></p>	<p>Family can access psychosocial supports but out of pocket costs, waitlists, shortage of specialists</p> <p>Parents not involved in developing policies, procedures or review of materials</p> <p>Little attention given to indigenous languages</p>	<p><b>Parents' involvement</b></p> <p><b>Increased engagement and training for parents</b></p>	<p>Family can access psychosocial supports but out of pocket costs, waitlists, shortage of specialists</p>	<p><b>Parents' involvement</b></p> <p>Parents were engaged in the development of policies, procedures to some extent</p> <p>Family advocacy groups make recommendations to community-based services</p>	<p><b>Partial convergence</b></p>
<p><b>Transition into adulthood</b></p>	<p><b>Services lacking</b></p> <p><b>Lack of adult psychiatrists and other specialists to transition to</b></p> <p><b>Reluctance to prescribe medication due to stigma</b></p> <p>No consistent policies or procedures</p>		<p><b>Services lacking</b></p> <p><b>Lack of adult psychiatrists and other specialists to transition to</b></p> <p>Lack of policies for transition to adult care</p>		<p><b>Convergence</b></p>
<p><b>Quality Assurance</b></p>	<p>No national policies or universal procedures – institutions only</p> <p>Data rarely collected – only for research</p> <p>Parents not engaged in national quality initiatives</p>		<p>No national policies or universal procedures</p> <p>Data rarely collected</p>	<p>Parents were engaged in national quality initiatives to some extent</p>	<p><b>Partial convergence</b></p>
<p><b>Discussion, debate and controversy</b></p>	<p><b>Incessant discussion about over medicalisation of ADHD</b></p> <p>Diagnosis not recognised as a</p>	<p><b>Increasing recognition that ADHD and learning disorders are common</b></p>	<p><b>Conflict between biological and social models of origins of ADHD</b></p> <p><b>Controversy over medicalisation</b></p>		<p><b>Partial convergence</b></p>

Requirements and models for supporting children with complex mental health needs and the primary care interface

	<p>neuro-biological condition by some</p> <p>Lack of recognition that ADHD causes significant impairment</p> <p>Lack of specialist services focussed on lifelong persistent, chronic conditions (much more on intervention based strategies)</p> <p>Lack of political will to provide funding and services</p> <p>Need more enthusiasm and recognition of the need for integrated services from practitioners</p>	<p>conditions</p> <p>Opportunity for advocacy as government willing to have some dialogue</p> <p>More funding for research</p>	<p>of ADHD</p> <p>Need more public awareness and advocacy</p> <p>Lack of awareness about the challenges of living with ADHD</p>		
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