



Models of Child Health Appraised (A Study of Primary Healthcare in 30 European countries)

Work Package 2: Final report on models of children's social care support across the EU and the relationship with primary health care

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Final report on models of children's social care support across the EU and the relationship with primary health care

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Origin

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Useful abbreviations

<i>CA</i>	Country agent
<i>ABI</i>	Acquired brain injury
<i>UNCRC</i>	United Nations Convention on the Rights of the Child
<i>CPRD</i>	Convention on the Rights of Persons with Disabilities
<i>AF</i>	Framework for the Assessment of Children in Need and their Families
<i>GIRFEC</i>	Getting it right for every child
<i>BBIC</i>	<i>Barns behov i centrum</i> (Swedish) translates to: Children's needs in focus

See Appendix B for a full glossary of terms related to the work of this report.

INTRODUCTION

The work of this task sits within the wider work of Work Package 2 which aims to outline safe and efficient interfaces of models of primary health care for children with complex care needs in the European Union (EU) and the European Economic Area (EEA). As such, this report is best understood in parallel with the work of other Work Package 2 tasks, and will be revised as necessary as that work completes. Children with complex care needs can be understood as children who require access to a substantial level of care as a result of one or more congenital, acquired or chronic conditions. The specific objective of this task is to understand the provision of social care support for this group of children and their families, and how such services interact with primary care.

Under the UN Convention on the Rights of the Child (Article 23), children with complex care needs have the right to additional supports so that they can live full lives. As such, they have the same right to go to school, have a safe and warm family environment, make friends and take part in leisure activities, as other children. In this work, these additional supports are described as social care needs and these needs are often met by services described as social care services. These services can be understood as the kinds of supports required to address the ‘everyday’ or ‘ordinary’ needs of children with complex health needs and are thus differentiated from health treatment or clinical support. The work of this task is timely as up until now there has been little research to examine the types of social care models in European countries for children with complex healthcare needs.¹To the knowledge of the authors this is the first time an extensive mapping and analysis of the legal and organisational context of social care services and the interface of these services with primary care has been undertaken for this population.

If the parents of a child with complex needs require additional support in providing their ‘everyday’ or ‘ordinary’ needs they will find themselves navigating different legal or organisational structures depending on which MOCHA country they live in. **Chapter 1** presents the background to this complex context including definitions of key concepts used within this report. This Chapter also contains a narrative review of the literature of the social care needs of children with complex care needs along with an overview of what has been written to date on social care across the EU. This task is concerned with the interface between social care services and primary care. In policy literature this interface is often described as integrated care and in order to contextualise this analysis there is an overview of conceptual models of such integration.

Chapter 2 describes the methodology used to gather information about how the social care needs of children are met in the 30 participating countries in the MOCHA project. The Chapter describes the questions that were asked and the approach to data analysis. The results of the data analysis are described in **Chapters 3** and **4** which attempt to explore the legal and organisational context of how social care needs of children with complex healthcare needs are met, and how countries are currently approaching the integration of primary and social care delivery.

¹ Much of the current literature from a social care perspective has tended to focus on the social care and long term needs of older people. (See Mot *et al.*, 2012; Leichsenring, 2004 Leichsenring *et al.*, 2013; Blackman *et al.*, 2001; Pfeiferová *et al.*, 2013; Boerma *et al.*, 2013).

Children with complex needs are some of the most vulnerable children in society; it is not surprising that they are shown to be significantly more likely to experience abuse and neglect than other children. This includes abuse by strangers, their peers, professionals and residential care services. It is perhaps easy to understand that their complex needs can place additional stresses and strains on the resources of those who care for them and that this may contribute to their vulnerability to harm. Safeguarding provisions for these children were explored in this task and are described in **Chapter 5**. As a lack of cooperation by professionals in different disciplines is thought to be a barrier to effective child protection, it is thus timely to outline the interface and coordination between primary care, social services and child protection services.

A key focus of this work is to explore the interface between primary care and social care for children with complex care needs, with the ultimate objective of contributing to a conceptual model of primary care for meeting the needs of all children. Hence the rationale for exploring integrated care in **Chapter 4**. A key theme emerging from the literature is the importance of keeping the service user at the heart of an integrated service design. Therefore, any model that encourages health and social care professionals to keep the needs of children at the centre of their interventions seems crucial. A model can provide a common language and understanding for health and social care professionals to share information and cooperate to ensure the wider needs of children with complex care needs are understood and supported and one such model, the *Framework for the Assessment of Children in Need and their Families*, is one of the potential facilitating practices which are explored in **Chapter 6**. **Chapter 7** provides an overview of the key overall themes emerging from this work and potential links to other work packages within the MOCHA project.

Chapter 1 Background

1.1 Introduction

This Chapter aims to provide an overview of a number of key concepts and themes that are the backdrop to the task of examining models of social care support and the social care interface with primary health care for children with complex care needs. This includes a review of entitlements to social care provision for all children, including those with complex care needs, and an overview of the literature with regard to integrated primary and social care services. As noted in the introduction, children with complex care needs are particularly vulnerable to abuse and neglect, therefore approaches to safeguarding are also explored.

1.2 Definitions, concepts and issues

1.1.1 Children with complex care needs

The definition of children with complex care needs varies in the literature. This report uses the term to refer to children who have substantial care needs as a result of one or more congenital, acquired or chronic conditions, with need of access to multiple health and social support services. These needs may be medical care needs, or mental health care needs. It also includes children with a brain condition that threatens or hinders an age-appropriate mental health development. Such children may have functional limitations which often required tailored technological assistance (Cohen *et al.*, 2011; Elias *et al.*, 2012). The term *children with disabilities* is also commonly used to describe children with complex care needs. Long-term disabilities *may* be expected as a result of these conditions.

What adds to the complexity of the care needs of these children is that they will require additional supports to live an “ordinary” life; for the purpose of this report these additional supports are referred to as social care supports (defined further in section 1.1.2). It is their dependency on others that potentially makes these children vulnerable to poor outcomes including abuse and neglect (as noted in the introduction, it is recognised that children with complex care needs may be more vulnerable to child protection concerns than other children - see section 1.1.2). Therefore, two other concepts are important background or contextual considerations: that of ‘child welfare’ and ‘child safeguarding’. The former refers to the type of social service supports that promote the child’s wellbeing; such interventions are necessary for the many children, including those with complex care needs, who are, in the words of the Children’s Act England and Wales, ‘unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services’ (Children’s Act, 1989; Section 17). (In the Children’s Act these children are termed ‘children in need’.) The latter refers to methods and interventions to protect children from unnecessary harm, abuse (emotional, physical, and sexual) and neglect; children who may be facing such harms are considered ‘children at risk’ and require the intervention of child protection services².

² It is recognised that if children and families are not adequately supported a ‘child in need’ may become a ‘child at risk’. Conversely, children at risk also require support to promote their welfare and address all their developmental needs.

1.1.2 Social Care Needs of children with complex care needs

Social care support for children with complex needs and their families is the care and support that enables them to have an 'ordinary life'. A comprehensive review on the social care needs of children with complex needs, conducted by Marchant *et al.* (2007), found that for children with complex health care needs, 'social care needs' can include the ability to enjoy friends and family, participate in school, engage in leisure and social activities and have a safe and happy home environment. For those children that require additional targeted supports to meet their broader social needs, many countries have developed policies and services. Such services are sometimes defined as social care services or personal social services.

A challenge when considering and conceptualising social care needs for children with complex care needs is that it is often difficult to disentangle social care needs from health care needs. Instead they interact in a complicated and multifaceted manner. This is a pivotal reason for the pursuit of integrated care for this group. Marchant *et al.* (2007) outline this difficulty clearly;

"Social care needs are very difficult to disentangle for this group of children and young people. Their healthcare needs are so much a part of their everyday lives that dividing their needs into different categories is untenable. Moreover, the wider needs of children and families are likely to be inextricably linked, including emotional, educational, and financial as well as primary care and social care needs. Concomitantly, professional roles and boundaries are often and necessarily blurred, that is, 'social care' needs are not necessarily met by social care agencies and 'healthcare' needs are not necessarily met by health services" (Marchant et al., 2007).

Safeguarding children with complex care needs

It is well established that children with complex needs are more likely to suffer neglect and abuse than other children (Jones *et al.*, 2012, Stalker and McArthur, 2012; Sullivan and Knutson, 2000; Sullivan, 2009.) The findings of a systematic review by Jones *et al.* suggest that children with disabilities are three to four times more likely to be victims of violence than children without disabilities (2012; 906). The studies included in this review, found that abuse could be perpetrated by family members, other adults, carers, and peers. Reasons for this included "societal stigma and discrimination, negative traditional beliefs and ignorance within communities, lack of social support for carers, type of impairment (e.g. communication difficulties), and heightened vulnerability as a result of the need for increased care, including medical attention" (Jones *et al.*, 2012; 899). The importance of multi-agency working when it comes to this population is outlined in UK practice guidance on safeguarding disabled children where it is pointed out that a lack of interdisciplinary work may lead to inadequate detection of abuse as "practitioners in child protection teams may have no specialised knowledge of disability, whilst disability specialists may have limited knowledge of child protection" (Murray and Osborne, 2009: 54).

1.1.4 Children's Rights

The vulnerability of children with complex needs to harm or poor outcomes is in the context of the increased vulnerability of children as a population. In light of this, legal frameworks have been established over the last few decades to ensure that children's rights are guaranteed through the law. In an international context, the United Nations General Assembly adopted the

Convention on the Rights of the Child (UNCRC) in 1989 and all members of the EU and EEA are signatories. The Convention, which includes special recommendations for children with disabilities, sets out the rights of the child to receive adequate care to ensure that their well-being needs are met and to be protected from harm, as well as emphasising the need to incorporate the wishes of the child in decisions that will affect their lives (UNCRC, 1989).

In addition, all but two countries (Ireland and the Netherlands) have ratified the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN in 2006. The CRPD aims to promote the rights of children with disabilities through ensuring that their best interests are upheld and that measures are taken to incorporate their views into the design of services. It makes provision to ensure all appropriate legislative, administrative, social and educational measures are taken to ensure persons with disabilities are protected from exploitation and abuse (CRPD, 2006). While EU member states must have due regard to the UN Conventions when designing any policy or legal framework which will impact on children, the rights of the child are further guaranteed by EU institutions, and by EU countries when implementing EU law, through the Charter of Fundamental Rights of the EU (2009) and the EU Convention on Human Rights (1953)³.

1.1.5 Social care services in Europe

There is no agreed definition of what social care services are but they can be referred to as 'help that is provided for any person of any age with a social care need, which hampers the person in some of his/her daily activities' (Neményi, Lamura, and Boškić, 2006; 5). In a European context, terms such as social services, social welfare, social protection, social assistance, social care and social work are used interchangeably, and therefore conceptual difficulties arise in regard to what 'social care services' mean in different contexts and countries (Munday, 2003). For the purposes of this task social care services encompass *personalised* support for individuals with specific needs.

Across Europe the concept of child wellbeing, as outlined in the over-arching frameworks securing children's rights, is incorporated into legislation for child services. Indeed there is often a focus on proactive rather than reactive measures to supporting vulnerable citizens, with many European countries adopting a 'child and family welfare' model as distinct from the model of 'child safety' commonly found in North America, Australia and Canada (Thoburn, 2013). This perspective implies that children's services should not simply focus on protecting children from abusive environments, but should promote their welfare and that of their families through addressing their developmental needs (Thoburn, 2013)⁴. It has been hypothesised that where a broadly 'child welfare' approach is in place, children are more likely to be identified as

³ The Charter of Fundamental as whole is applicable to children; articles relating specifically to children concern the rights of the child (Article 24), and the prohibition of child labour (Article 31) (EU Commission, 2009); the EU has also outlined the rights of children as part of the EU Commissions Social Investment Package. The Commission in 2013 published a framework which aims to meet the rights and best interests of the child; called 'Recommendation: Investing in Children – Breaking the Cycle of Disadvantage', this framework outlines policies to tackle child poverty and promote child well-being. It is based on three pillars; "access to adequate resources, access to affordable quality services and children's right to participate" (EU, 2013).

⁴ The movement towards interdisciplinary child wellbeing and family support services has been driven by recognition of the need for a holistic approach to service provision to improve child outcomes and life chances among disadvantaged and vulnerable populations (Lara Montero *et al.*, 2016).

vulnerable and receive help than in countries with a narrower ‘child safety’ approach (Thoburn, 2013; 233). The OECD reports that a family and child-centred model is commonly found in the Nordic countries where family centres have been established offering free, universal, cross-sectional health, educational and social services (2015).⁵

The literature shows that in many cases children’s social care needs are addressed by their parents or carers who might utilise the existing “universal” social supports, e.g. schools, sports clubs etc. However, some parents/carers need additional targeted support to help them to meet the needs of their children (Paget, 2010; Marchant et al. 2007). Therefore, a key distinction to make when considering the provision of social services is the design of universal and targeted services. In universal systems, all families are eligible to receive services, whereas in a targeted system only those with the greatest needs and/or limited means are eligible for support. In some systems, a cascade model operates (Nordic countries as an example), whereby universal services encompassing a preventative approach are available to all families, and more targeted, specialised and tailored support is available to families and children with complex needs (European Social Network, 2016). The Hardiker Model (1991) (outlined in Figure 8, Appendix D) is an example of this type of service design (Owens, 2010; Lara Montero *et al.*, 2016; Thoburn, 2013). In this model, the levels range from universal preventative and social development services to intensive and long-term support for children and families with complex needs; children and families move up and down the pyramid depending on the level of intervention required.

However although a highly developed approach is recognised in international policy frameworks, and is adhered to practice in some European countries, it has been recognised that in some cases more needs to be done in order to ensure that the needs of children with complex needs and their families are met; there is evidence from within-country studies in different MOCHA countries suggesting that the financial, emotional, family support and social well-being needs of such children and their families often go unmet (Brenner *et al.*, 2015; Marchant *et al.*, 2007). Furthermore, when it comes to safeguarding needs, it is clear that the needs of children with complex needs are not being fulfilled in this respect. A recent review by the Fundamental Rights Agency (FRA) stated that there are significant inadequacies in current child protection systems in European Member States which often fail to protect children with disabilities from abuse and violence (2015a). The report highlighted the need for concrete objectives for coordination between the various services to safeguard children with disabilities from violence and abuse (FRA, 2015a), noting that systems often fail to address the particular risks faced by children with disabilities, or do not involve professionals who have the knowledge required to identify potential risky situations and support children with disabilities who are victims of abuse or neglect. It was also found that many member states have insufficient preventative measures, such as interventions to support parents of children with disabilities in their caring role - for example, respite services (FRA, 2015a).

For children with complex care needs, it is likely that support may be accessed via a variety of service providers. It is recognised that integration of social and primary care is an optimal model for this population and at a European level one of the most commonly recognised

⁵ In a number of other European countries similar centres have been established in some regions but do not operate nationwide – this is the case in Belgium, the Czech Republic, France, Germany, Italy, the Netherlands, Poland and Slovenia (OECD, 2015; 60).

versions of integrated primary and social care is multidisciplinary primary care.⁶ Some of the other ways in which primary care and social care for children with complex care needs can be provided in an integrated form include; joint planning and decision-making; placement schemes, such as social workers working in primary care; centre-based services or co-location delivery, where professionals from different agencies work together in one site; multidisciplinary teams, where professionals from different agencies work together on a day-to-day basis as a team; and case-management, where a professional has responsibility for ensuring a co-ordinated service for families (Lara Montero *et al.*, 2016). An OECD report on integrated care outlines the benefits of a case worker approach; as professional care workers are better able to navigate through the system and communicate with service providers, such approaches facilitates service users by ensuring that their broad needs can be professionally evaluated earlier (2015; 23). In order to make sense of the different forms of integration in practice, as outlined above, it is worth exploring further the concept of integrated care.

1.1.6 Forms of integration

An overarching theme in any discussion on integration, is the patient or service user experience. The WHO asserts “there is no ‘one model’ of people-centred and integrated health services” (2015; 9), but that people-centred care should be viewed as a design principle: “People-centred care should be viewed as a service design principle [for strategies to enhance access and encourage universal health coverage, and primary and community-based care]” (2015; 19). Thus integrated care is about the service user experience, and not about ‘structures, organisations or pathways’ (Monitor, 2012). The nature of the integration of care will depend on local factors: “such as existing policy, inter-agency agreements and resources” (King and Meyer, 2006; 478).⁷

For the purpose of this task it is useful to explore the concept of integrated care as it relates to primary care and social care integration provided by review of the recent literature⁸ (for a more detailed synthesis of the dimensions of integration of care see the 2016 WHO report ‘Integrated care models: an overview’.) Services can be integrated either horizontally or vertically – this is referred to as breadth of integration. Vertical integration refers to link between services at different levels of care, for example integrating hospital and community-based health services to ensure the continuum of care (the focus of task 2 of this MOCHA work package which looks at the integration of primary and secondary care for children with complex care needs), while horizontal integration refers to the bringing together of services, professions and organisations operating in different sectors at the same level of care. The aim of this task is to examine the horizontal integration of primary care and social care services for children with complex care needs.

When it comes to the processes’ of integration, namely how integration works in practice, Fulop’s typology of integration is oft-cited in reviews of integration (see Lewis *et al.*, 2010; Pike and Mongan, 2014; Curry and Ham, 2010). Six types of integration are specified;

⁶ A recent study focusing on child health systems, found that many European countries deliver some care through multidisciplinary teams (including social care professionals) (Wolfe *et al.* 2014); the Netherlands, Norway, Germany, Italy, Finland and the UK are where the most established multidisciplinary primary care is found (Wolfe *et al.* 2014).

⁷ The influence of national differences, due to, for example, differing cultural, economic and social history, on primary care models is acknowledged in the MOCHA WP1 report on models of primary care (Blair *et al.*, 2016;23).

⁸ See in particular WHO, 2016; Pike and Mongan, 2014; Curry and Ham, 2010; Lewis *et al.*, 2010.

normative, organisational, functional, service, clinical, and, where there a coherence of rules and policies at all of the latter four levels, *systemic* (Lewis *et al.*, 2010).⁹ Lewis *et al.*, (2010) present Fulop's typology in diagrammatic form (see Figure 1), which gives an explanation of how integration is manifest at these different levels. Clinical/service level integration¹⁰ has been posited as the most important level in the literature (Pike and Mongan, 2014; Darker, 2013); the service and clinical levels are the levels at which service users have direct contact with an integrated care system.

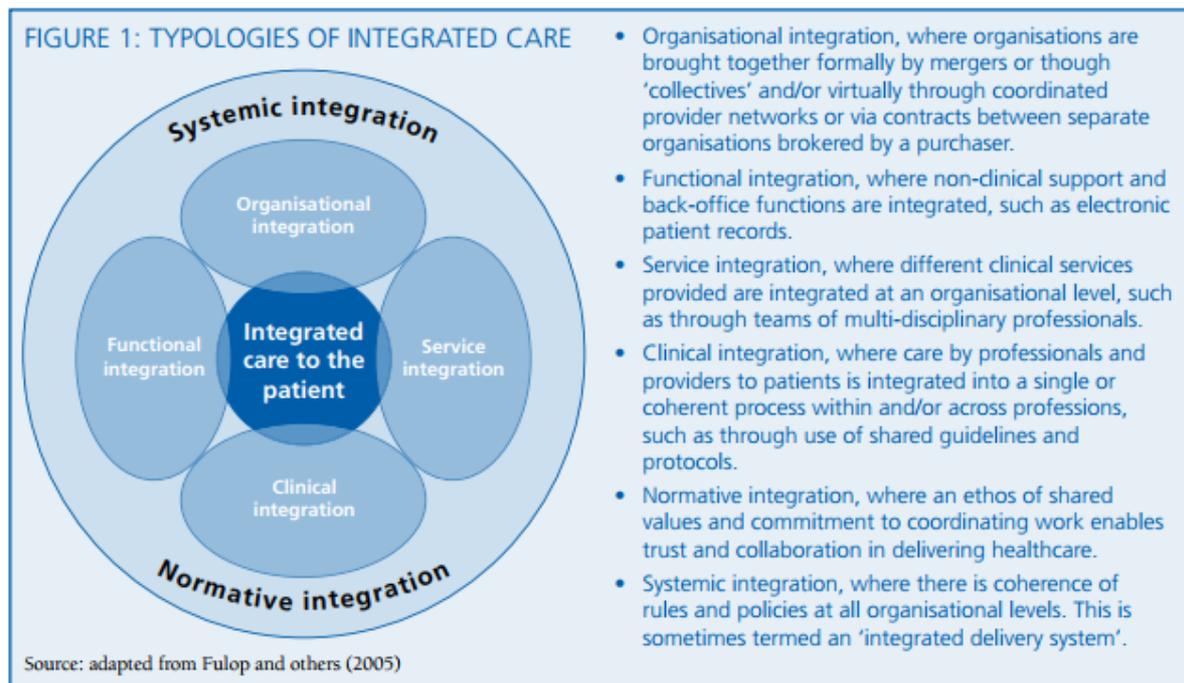


Figure 1: Fulop's typology of integration (from Lewis *et al.* 2010;12)

Integration is also often referred to as *real* or *virtual*; a broad definition of these concepts is that real integration means that organisations merge their services, while virtual integration means that providers work together through networks and alliances. Real integration can be thought of as organisational, while virtual integration can be thought of as contractual (Curry and Ham, 2010;4). Leutz (1999) identified three degrees of integration ranging from *linkage* – where coordination is on an ad-hoc basis, to *co-ordination* – where integration is structured with defined methods of communicating and collaborating, to *full integration* – where a new entity is created that consolidates funding and service provision (Leutz, 1999; 84-88). In practice co-ordination is somewhat akin to virtual integration, and full integration to real integration.

In addition to these layers of integration, Curry and Ham conceptualise levels of integration which involve the classification of different populations. These levels are *macro* – where an entire population receives integrated care, *meso* – where a population with a particular illness or disease receives targeted, integrated care, and *micro* – where individual service users receive targeted care in an integrated fashion². The authors note that in practice these levels are often

⁹ Fulop's work has been further advanced upon or refined by different authors and five types of integration are often described in the literature - *organisational, normative, administrative, clinical, and systemic*- as in Shaw, Rosen and Rumbold, 2011.

¹⁰ Clinical/service level integration - an understanding of levels of integration which combines these two levels is presented in Pike and Mongan, 2014 and Darker, 2013

targeted in combination. Primary care and social care integration would generally be at the micro level in this conception of integration; care co-ordination, care planning, and use of technology are some of the integrative approaches identified at the micro level. Table 1 presents the different ways in which integration can be understood:

Table 1: Conceptualisations of integrated care

Understanding 'Integration'	
Lens through which integration can be understood	How integration is classified at this type/level
<i>Breadth</i>	Vertical or horizontal
<i>Degree</i>	Linkage Coordination Full integration
<i>Form</i>	Virtual or real
<i>Type or level</i>	Systemic Organisational Service Clinical Functional Normative
<i>Level</i>	Macro Meso Micro

Challenges to Integration

A fundamental reason behind why integration of primary care and social care can be difficult to achieve in Europe is addressed in a 2008 WHO report. The report describes how European health systems are often administered on a national basis “within the framework of a national health system (such as Greece, Italy, the Nordic countries and the United Kingdom) or a national social insurance system (such as Austria, France, Germany and the Netherlands)” (2008; 23). Meanwhile social welfare systems are often administered at the local level by regional or local government (see Chapter 9 of the final report from Work Package 1 for a discussion of the concept of multi-level governance as it relates to primary care (Blair *et al.*, 2016)). This means that primary care and social care are understood and defined in different ways. Accordingly, different accountability and performance management regimens and targets may result from the different legal arrangements and funding bodies of the different sectors (WHO, 2008; 23). The WHO has also considered challenges to the integration of whole health systems and made a number of recommendations for achieving people-centred healthcare (see WHO report on people-centred care, 2015).

When it comes to the integration of health care with wider social care systems in European countries, including housing and education (a broader focus than that of this report), the practical challenges have been documented by the OECD (2015), European Commission (2012),

Council of Europe (2012) and the European Social Network (2016). A consistent theme identified in these reports are that cultural, organisational, information and financial barriers to the integration of care across health, education, housing and social care agencies are experienced in European countries. The OECD report, for instance, looks at how social services for vulnerable groups are integrated across developed countries with a focus on four groups of vulnerable populations: children and young people with mental health difficulties, disadvantaged and vulnerable families, homeless populations, and older people, and finds that factors which can hinder the implementation of integrated models of service delivery are: governance challenges, cultural and professional challenges, information challenges, delivery challenges, and financial challenges (OECD, 2015).

Summary of Background

- Children with complex care needs may require both primary care and social care supports.
- The complexity of needs within this population makes them more vulnerable to poor outcomes, including abuse and neglect.
- From a human rights perspective, these children have the right to the level of support required for them to achieve better outcomes.
- Services for children with complex needs may come under the remit of different organisational and legal structures.
- The WHO suggests that the organisational structures for health and social care should be designed so as to provide people-centred care and lead to improved outcomes.

Chapter 2 Methodology

2.1 Aims and objectives

The main aim of this task is to understand the social care interface with primary health care for children with complex care needs and their families in the 30 MOCHA countries. The research objectives are as follows:

- 1) Map social care policies and services for children with complex needs in Europe using documentary analysis and information from 30 local country agents by focusing on the care pathway for children with complex needs who have social care needs.
- 2) Outline safeguarding policies and procedures in primary care for children with complex needs at risk of abuse across 30 European countries.
- 3) Examine how primary health care services interact with social care services in 30 European countries.
- 4) Identify the facilitators and barriers to integrated primary care and social care for children with complex health needs.
- 5) Identify and describe optimal models of social care for children with complex needs in the European context.
- 6) Complement this work with data gathered from other tasks within MOCHA Work Package 2.

The next section of this report outlines the methodological approach undertaken by the research team to address these research objectives.

2.2 Overview of methodology

A key methodological feature of the MOCHA project is the remunerated retention in each study country of a part-time Country Agent – a local expert in child health services, who acts as the agent for obtaining from local indigenous source data requested by the principal scientists in the project¹¹. Questionnaires on social care for children with complex care needs were sent to the 30 MOCHA Country Agents in May 2016 and data collection was completed between June 2016 and March 2017 (see Appendix A for a full replication of the questionnaire). 24 countries responded¹² and in Chapters 3-5 a descriptive analysis of this data in the context of the background literature on social care (including that on child safeguarding) and on primary and social care integration is presented.

2.3 Country Agent questionnaire

2.3.1 Questionnaire design

The questionnaire was developed by the task researchers and informed by review of the background literature, the systematic literature review on ABI, and expert knowledge of the research team. Divided into three parts it utilised a mixture of open and closed ended questions. The first section sought to understand the national context within which social care services for children with complex needs are provided, as well as how social care provision is integrated

¹¹ For a list of country agents see: <http://www.childhealthservicemodels.eu/partnerlisting/country-agents/>

¹² Belgium, Bulgaria, Denmark, France, Luxembourg and Slovenia were the six countries which had not responded by the date of analysis.

with primary care. The design of this section was guided by current internationally agreed standards of quality in social services as outlined in the Common Quality Framework for Social Services of General Interest (CQF for SSGI). The CQF for SSGI describes a set of domains, preconditions and principles, as well as key criteria that influence the quality of social services¹³; the manner in which they were developed allow the criteria to be responsive to particular legislative, cultural and socio-economic contexts; therefore, the CQF for SSGI intends to be flexible enough to be applied to social services that are organised at the regional or local level of all EU member states (CQF SSGI, 2010: 4)¹⁴. Informed by this framework, this section of the questionnaire dealt with the contextual factors of social care service structure and delivery for children with complex care needs, including a supportive policy and legislative framework, sustainable funding, and integration with primary care.

The second part of the questionnaire focused on the care pathway of a child with a complex health condition requiring social care support. The aim of this section was to provide a map of social care services and how these link with primary care services in the community. Case scenarios or vignettes were used to achieve this objective. The case scenarios were originally developed by the task 2 team of Work Package 2 and were adapted by task researchers to explore social care needs (the task 2 team are looking at care of children with enduring complex conditions at the acute/community care interface). The advantage of this approach is that the scenarios provide concrete examples within which respondents can contextualise their response. In cross national research it allows for the analysis and comparison of different countries interpretations of a 'uniform' situation (Barter and Renold, 1999). The primary focus of the scenario section of the questionnaire was to explore how a number of social care needs might be conceptualised and responded to in different countries.

It is necessary to consider the 'ordinary' or 'everyday' needs of children with complex care needs separately from the needs of those requiring safeguarding from abusive environments. Thus the interface between primary care and child protection services was examined separately in the third section of the questionnaire. The aim of this section was to understand the procedures in place when a suspected case of child abuse is identified in primary care. It also deals with access to appropriate and specialised care for children with complex needs if family breakdown occurs. Case scenarios or vignettes were again used; in this scenario, the child in the vignette, Luke, is identified as a child at risk when a child protection concern is raised during a GP visit. The scenario was developed in line with a number of reports outlining the most appropriate mechanisms for identifying and responding to cases of child abuse in the context of disability (see FRA, 2015a; Murray and Osborne, 2009).

2.3.2 Validation and distribution

Questions coming from MOCHA work packages are first considered by the Principal Investigator (PI), Deputy PI, and Research Coordinator, then passed to a technical sub-group of the project's External Advisory Board for validation. This means that questions distributed to Country Agents have passed through internal and external scientific scrutiny to confirm their rationale,

¹³ It includes the following aspects of service design and delivery: contextual factors, organisational factors, services delivery process, and outcomes.

¹⁴ The CQF for SSGI was developed through a process of consultation and collaboration, involving a number of contributing partners representing a wide mix of different social services and different stakeholders at European and National level. This group consisted of service user organisations, service provider organisations, funders of social services, policy makers, quality accreditation organisations, universities and local authorities (CQS SSGI, 2010: 4).

relevance, and clarity. MOCHA Country Agents were asked to complete the questions on the basis of their expertise or, in cases where this was not possible, to gather data from other sources/national experts on individual questionnaire items.

2.3.3 Approach to data analysis

Data were initially compiled and coded according to the responses alone, and then re-evaluated based on other sources (policy documents, guidelines, other empirical evidence, literature reviews, and expert opinion) (following guidance of Svevo-Cianci *et al.*, 2010). Coding was finalised based on values established applying the multiple sources of information used to ensure maximum comparability of social care support for children with complex care needs across European countries (also following guidance of Svevo-Cianci *et al.*, 2010). After the initial data analysis, the country agents were contacted again and asked to provide clarification or further explanation on specific responses. At this stage consensus was agreed between the task researchers and CA on the coding scheme. The next section outlines the findings from the country agent questionnaires.

Chapter 3 Mapping Social Care Support for Children with complex care needs in European Countries

3.1 Introduction

If children with complex care needs have a right to social care supports to enable them to have an ordinary life, and to protection from neglect or abuse, it might be expected that this will be reflected in the legal, policy and organisational structures across the participating countries. This Chapter outlines how social care is formulated in legislation and policy at state-level, and how it is organised and structured, throughout the MOCHA countries. This Chapter also outlines how primary care and social care systems coordinate for child protection purposes, and how children with complex care needs with communication difficulties are facilitated in the event of a child protection concern.

3.2 Legal entitlement and policy for social care for children with complex care needs

As Table 2 demonstrates, in all MOCHA countries a legal framework for the provision of social services has been established; most of these are national level frameworks - with the exception of Austria, Germany and Spain which have federal (Austria and Germany) or regional (Spain) laws for social services. In most MOCHA countries there is a legal entitlement to special and specific social care support for children with complex care needs (in all countries this is defined as *children with disabilities*); in many cases this is provided through a specific social care or social welfare law. Supports stipulated in such frameworks include personal care/assistance, financial support, psycho-social interventions and programmes, family support and educational supports (see Table 2). Both the Netherlands and Germany describe how different acts, or articles within acts, will apply depending on the complexity of needs of the child; in the Netherlands, the needs of the majority of children will be met by the provisions of the Child and Youth Act, 2015, however in the event that a child should need long-term support, the Long Term Care Act, 2015 will instead apply.

While many (but not all) respondents described a specific social care law outlining citizen's entitlements to social services including personal assistance (such as the Social Services and Social Assistance Law, 2002 in Latvia and the Social Welfare Act, 2009 in Norway); when asked particularly about laws covering the provision of social care for children with complex needs, a number of respondents made reference to other laws which must be considered alongside such a principal social care law in order to capture the totality of social care provision for this population. The Icelandic respondent, for instance, when asked about provision of social care for children with complex needs, notes a law relating to the protection of the rights of disabled persons; two laws relating to general social assistance (the Municipalities' Social Services Act, 1991 and the Social Assistance Act, 2007); and a law on schooling.

3.2.1 Legal entitlements for safeguarding

All the MOCHA countries report having a child protection framework which provides a legal standing for the protection of all children from abuse¹⁵; as Table 2 shows, six countries make special recommendations on promoting the welfare of children with disabilities within their child protection legislation (Estonia, Ireland, Latvia, Lithuania, and Romania and the UK (England)), where actions aimed at preventing impairment of children's health and development are outlined. (Legislation in the Czech Republic and Norway also includes some guidance/rules on promotion of the welfare of children with disabilities). Furthermore, a number of the MOCHA countries provide specific guidance on safeguarding and protecting children with complex health care needs in child protection legislation; in some countries direct reference to children with disabilities is made in the legislation but specific procedures or objectives are not outlined (Portugal as an example), while in some cases the respondent notes that regulations outline a case oriented approach in which disability would be a key consideration when adopting a care plan and strategy (Finland is such an example). In ten of the MOCHA countries, child protection legislation does not make direct reference to children with disabilities; instead the respondents from these countries note that the legislation outlines the same provisions for all children.

¹⁵ See Table B1, Appendix B for more detail on child protection legislation in the MOCHA countries

Table 2: Legal entitlement to social care for children with complex care needs in European countries

	Social Care Legislation	Special provision for children with complex care needs within social care legislation	Child protection legislation	Measure to promote the welfare of children with complex care needs within child protection legislation	Financial entitlement in social care legal framework	Home help OR personal care entitlement in social care legal framework (HH) (PC)	Family Support entitlement in social care legal framework	Educational entitlement in social care legal framework	Psychosocial entitlement in social care legal framework
	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>
Austria	Yes (Federal) ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^a	No ^a	Yes (HH) ^a	Yes ^a	No ^a	Yes ^a
Croatia	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^a	Yes ^a	Yes (HH) ^a	Yes ^a	Yes ^a	Yes ^a
Cyprus	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^a	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Czech Republic	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Other (recommendation applicable to children with physical disabilities) ^{ab}	Yes ^{ab}	Yes (HH) ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Estonia	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^a	No ^a	No ^a	No ^a	No ^a
Finland	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Germany	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^a	No ^{ab}	Yes (HH) ^{ab}	No ^{ab}	Yes ^{ab}	Yes ^{ab}
Greece	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^a	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Hungary	Yes ^a	No ^a	Yes ^{ab}	No ^a	Yes ^{ab}	No ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Iceland	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	*	Yes ^{ab}	No ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Ireland	Yes ^{ab}	Other ^{ab}	Yes ^{ab}	Yes ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Italy	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^{ab}	Not applicable ^{ab}	Not applicable ^{ab}	Not applicable ^{ab}	Not applicable ^{ab}	Not applicable ^{ab}
Latvia	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^a	Yes (HH) ^a	No ^a	No ^a	Yes ^a
Lithuania	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^{ab}	Yes ^{ab}

Malta	Yes ^{ab}	Other ^{ab}	Yes	*	*	*	*	*	*
Netherlands	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Norway	Yes ^{ab}	Other ^{ab}	Yes ^{ab}	Other (the law allows the social welfare board to instigate a treatment order for children with disabilities or who need extra help if parents fail to ensure they receive necessary services) ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Poland	Yes ^{ab}	Other ^{ab}	Yes ^{ab}	No ^a	Yes ^{ab}	No ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Portugal	Yes ^{ab}	No ^{ab}	Yes ^{ab}	No ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Romania	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes (HH) ^{ab}	No ^{ab}	No ^{ab}	Yes ^{ab}
Slovakia	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	*	Yes ^{ab}	Yes (HH) ^{ab}	No ^{ab}	Yes ^{ab}	Yes ^{ab}
Spain	Yes (Regional) ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^{ab}	No ^{ab}	No ^{ab}	No ^{ab}	No ^{ab}	Yes ^{ab}
Sweden	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	No ^{ab}	Yes ^{ab}	Yes (HH) ^{ab}	No ^{ab}	No ^{ab}	Yes ^{ab}
UK (England)	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

^a Country agent response ^b Policy documentation (See Appendix 3) ^c Research literature ^d Other external information sources. * Insufficient information provided.

3.3 Organisational structure and social care policy for children with complex care needs

In almost all MOCHA countries there is a formal model of social care provision underpinned by legislation (see Table 3, column 1); however although there is significant variation in the way this care and support is delivered at local and community levels. Funding for social care support varies throughout the MOCHA countries. In many MOCHA countries social care is provided by a regional level of government; in some of these cases social care is also funded by the regional level (as in Sweden where it is funded by the municipality taxes), and in other cases it is funded through central taxation (as in Spain and the Netherlands where funds from the national budget are transferred to the regional level). In Norway funding is provided from both national and municipal taxation, as well as through national insurance. Social insurance or social security is also mentioned as a funding element of social care services in other MOCHA countries (Austria, Lithuania, Portugal) - different aspects of social care are likely to be funded through different means and the Austrian respondent points out that social security funds financial supports in Austria such as the care allowance. Many respondents mentioned the important role of NGOs when asked about social care funding; in many cases NGOs have a contract with the state to provide social care services (this is mentioned by respondents in Finland, Iceland and Ireland). In some cases however much of the NGO provided-services are provided without funding from the state (such as in Greece and in Slovakia).

In some MOCHA countries a central coordinating agency will guide social care provision which is then often implemented by regional social services. In Estonia, Greece, Ireland¹⁶, Malta and Norway there is a central state agency or organisation responsible for the coordination of social care support for children with complex health conditions/disabilities (see Table 3 below; for more detailed information see Table B1, Appendix B) – this is the SAPPOR agency in Malta, and the Social Insurance Board in Estonia. Meanwhile, in Croatia, Cyprus, Portugal and Slovakia responsibility for the coordination of social care support for children with complex health conditions/disabilities lies with a government ministry or ministries; in Cyprus the Department of Social Inclusion of Persons with Disabilities is responsible for social care services for children (and adults) with complex health care needs. Aiming to promote social protection, social inclusion and employment, the department consists of four sections; one in charge of management of the system for the assessment of disability and functioning; one with the remit of providing social benefits; another looking after vocational training and other support services; and one which is responsible for ensuring the implementation of the UN CRPD.

The amount of control over social care policy which a regional or local level of government in a country has will depend on the governance arrangement in that country. The Netherlands is an example of a country where social care is directed by a regional level of government – the municipality in this case. In the United Kingdom (England), devolved local government (Local Authorities) have the legal responsibility for the provision of social care to children with complex care needs. However, if a child has a continuing healthcare need the NHS clinical

¹⁶ The Irish CA notes that while macro structure of social care services for children with complex care needs are coordinated by the Health Service Executive (HSE), the operational management of services is coordinated and managed locally – funding is also provided by the HSE.

commissioning groups¹⁷ are responsible for organising care and support; the NHS has statutory responsibility for meeting the healthcare needs of children with complex needs and must link with Local Authorities with regard to these children. Decentralised forms of government will sometimes will have a significant role in formulating policies for their own regional area and in Poland, for example, the Voivodship Social Policy Strategy 2014-2020, which guides social policy at a voivodship or provincial level, is formulated by the voivodships in tandem with national government. Social care provision is then commissioned to lower levels of government, the powiat and gmina (roughly translating to county and municipality).

Types of provider vary significantly within and between countries. For example, care for children with complex needs can be accessed via local social care, community rehabilitation services, disability services, home care, child and family services, special educational services and other school based services (for example a school psychologist or social worker), primary care, and mental health services (sometimes located in primary care; Finland as an example). In most cases care is provided by a combination of these services, not necessarily working collaboratively. The needs of the child will often be a factor determining where they receive their care. In Germany, for example, the majority of care for children with complex secondary care needs, such as those associated with neurological conditions and more severe disability, is delivered via social paediatric centres. Most children with non-neurological conditions requiring complex care, such as diabetes, receive a limited extent of care in tertiary centre clinics, while children with complex mental health conditions receive care in child social-psychiatric ambulatory care.

3.3.1 Role of external organisations

In most countries, social care for children with complex care needs is also provided by not-for-profit NGOs with many countries also outsourcing to commercial organisations (for example private counselling services or respite care). Every MOCHA country outsources some health and social care services to non-profit organisations and seventeen countries also outsource care to commercial organisations (see Table 3, column 3). In the Netherlands, most social care is provided by non-governmental not-for-profit organisations. In a similar manner to Germany, most of these are provided by welfare organisations, or affiliated to Protestant or Catholic churches, many of which offer very comprehensive social services. In Slovakia, NGOs step in when the state doesn't provide support, for example, when a child doesn't reach the necessary degree of severity to qualify for state-support.

Table 3: Organisation and structure of social care for children with complex care needs in European Countries

	Formal model of social care	Central authority responsible for the coordination of social care for children with complex care needs	Outsourcing of social care for children with complex care needs
	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Not for profit/Commercial</i>
Austria	Yes ^{ab}	No ^{ab}	NGOs ^a
Croatia	Yes ^a	Yes (govt. dept.) ^{ab}	NGOs ^a

17 'Clinical Commissioning Groups are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. There are now 207 CCGs in England' (NHS, 2016).

Cyprus	Yes ^{ab}	Yes (govt. dept.) ^{ab}	NGOs ^a
Czech Republic	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
Estonia	Yes ^{ab}	Yes (agency) ^{ab}	NGOs & Commercial ^{ab}
Finland	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
Germany	Yes ^{ab}	No ^{ab}	NGOs ^{ab}
Greece	Yes ^{ab}	Yes (agency) ^{ab}	NGOs & Commercial ^{ab}
Hungary	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^a
Iceland	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^a
Ireland	Yes ^{ab}	Yes (agency) ^{ab}	NGOs & Commercial ^{ab}
Italy	Yes ^{ab}	No ^{ab}	NGOs ^{ab}
Latvia	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
Lithuania	Yes ^{ab}	No ^{ab}	NGOs ^{ab}
Malta	Other (mixed) ^a	Yes (agency) ^a	NGOs & Commercial ^a
Netherlands	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
Norway	Yes ^{ab}	Yes (agency) ^{ab}	NGOs & Commercial ^{ab}
Poland	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
Portugal	Yes ^{ab}	Yes (govt. depts.) ^{ab}	NGOs & Commercial ^a
Romania	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^a
Slovakia	Yes ^{ab}	Yes (govt. dept.) ^{ab}	NGOs & Commercial ^a
Spain	Yes ^{ab}	No ^{ab}	NGOs ^a
Sweden	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}
UK (England)	Yes ^{ab}	No ^{ab}	NGOs & Commercial ^{ab}

^a Country agent response ^b Supporting policy documentation ^c Supporting research literature

^d Other external information sources * Insufficient information provided

3.4 Safeguarding Procedures in Primary Care for children with complex care needs in European Countries

Using information from research completed by the FRA (2015b), along with data from the Country Agents this section draws together the framework for safeguarding children with complex health conditions (defined as children with disabilities in this context) from abuse. An understanding of the policies and procedures in place to identify and respond to cases of suspected abuse that present in the primary care setting was sought. Table 4 shows that in almost all countries there are guidelines for primary care professionals on reporting cases of abuse to the relevant authority (social services and/or justice authority depending on severity) (see Table 4). Similarly, almost all countries have established reporting and referral systems between primary care and social care, as outlined in Table 4. This can refer to a named person in primary care who is responsible for making the necessary referral to child protection services, or provisions to share data between primary care and child protection services. This can also refer to the establishment of a multidisciplinary case committee (led by a child protection social worker), where the child's GP or paediatrician can be part of this committee.

In twelve MOCHA countries (Austria, Croatia, Cyprus, Czech Republic, Greece, Ireland, Italy, Lithuania, Norway, Spain, Sweden, and the UK (England)), special procedures or supports are available when a child has communication or cognitive impairments and a safeguarding concern is raised (as outlined in Table 4); this usually refers to the provision of interpreters or psychologists to incorporate the wishes of a child with communication difficulties into the child protection process. It can also refer to special safeguarding training for particularly vulnerable groups, including children with disabilities - this is available in the UK (England).

Table 4: Safeguarding policies and procedures for children with complex needs in European Countries

	Guidelines on reporting procedures by GP/primary care professionals on suspected cases of abuse	Established reporting system between primary and social care	Special procedures for children with communication / intellectual impairments
	<i>Yes/ No/ Other</i>	<i>Yes/ No/ Other</i>	<i>Yes/ No/ Other</i>
Austria	Yes ^{abc}	Yes ^{ab}	Yes ^a
Croatia	Yes (mandatory) ^{abc}	Yes ^{ab}	Yes ^a
Cyprus	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Czech Republic	Yes ^{ab}	Yes ^{ab}	Yes ^{ab}
Estonia	Yes (mandatory) ^{abc}	Yes ^{ab}	No ^a
Finland	Yes ^{ab}	Yes ^{ab}	No ^a
Germany	Yes ^{ab}	No (No mandatory reporting system) ^a	No ^a
Greece	Yes ^a	Yes ^a	Yes ^a
Hungary	Yes (mandatory) ^{abc}	Yes ^{ab}	No ^a
Iceland	Yes ^{ab}	Yes ^{ab}	No ^a
Ireland	Yes (mandatory) ^{abc}	Yes ^{ab}	Yes
Italy	Other (regional/ local variation in reg.) ^a	Other (regional/ local variation in reg.) ^a	Yes ^a
Latvia	Yes ^{ab}	Yes ^{ab}	No ^a
Lithuania	Yes (mandatory) ^{abc}	Yes ^{ab}	Yes ^a
Malta	Yes ^b	Other (there are no explicit procedures) ^a	Other (No procedure but assistance may be available) ^a
Netherlands	Yes ^{ab}	Yes ^{ab}	No ^a
Norway	Yes ^{ab}	Yes ^A	Yes ^a
Poland	Yes (mandatory) ^{abc}	Yes ^{ab}	No ^{ab}
Portugal	Yes ^{abc}	Yes ^{ab}	*
Romania	Yes (mandatory) ^{abc}	Yes ^{ab}	Other (regional variation in availability of specialized help) ^{ab}
Slovakia	Yes ^a	Yes ^a	No ^{ab}
Spain	Yes (mandatory) ^{abc}	Yes ^{ab}	Yes ^a
Sweden	Yes (mandatory) ^{abc}	Yes ^{ab}	Yes ^a
UK (England)	Yes ^{ab}	Yes ^{ab}	Yes ^a

^aCountry agent response ^b Supporting policy documentation ^c Supporting research literature

^dOther external information sources * Insufficient information provided

Summary of mapping social care support for children with complex needs

- Special entitlements for children with complex care needs are included in social care legislation in half of all MOCHA countries.
- Social care provision is often the responsibility of the regional level of authority.
- Support is provided through a variety of organisations and services; important factors affecting the location of care received include the child's need; regional variation in service availability; and the overall social care resources/capacity
- Every MOCHA country outsources some health and social care services to non-profit organisations and 17 countries outsource to commercial organisations as well.

- Some countries make specific reference to the heightened risk of abuse among children with disabilities in their child protection framework and provide specific objectives to protect this group of children.
- Almost half of the MOCHA countries have special procedures or supports available when a child has communication or cognitive impairments.

Chapter 4 Case scenario: Support for a child with an acquired brain injury (ABI)

4.1 Introduction

This Chapter presents an analysis of how social care support is provided to children with the specific tracer condition of ABI. The information in this section is drawn from the second part of the questionnaire which describes the scenario of Luke, an adolescent who has sustained a brain injury following an accident. In order to understand how Luke and his family's social care needs are met in the community, questions to the Country Agents focused on how and when planning for Luke's social care needs take place, who is responsible for arranging access to those supports, and the comprehensiveness of social care supports in the community.

4.2 Support for a child with an acquired brain injury (ABI)

4.2.1 Rehabilitation support

Rehabilitation for a child who has undergone an accident causing brain injury is facilitated in many of the MOCHA countries. Often within a country there will be number of different options through which Luke can receive his rehabilitation treatment including; treatment in a rehabilitation centre, treatment provided as an outpatient service by a rehabilitation centre, and treatment provided as an outpatient service by a hospital. In a number of countries NGO's provide rehabilitation services and in a few countries there are also privately-run rehabilitation centres. A major factor affecting the care available is the area in which the child lives, whether urban or rural. Reduced access to rehabilitation care in rural areas is something that is mentioned specifically by the Hungarian, Romanian, Lithuanian and Czech respondents, while the Greek and Norwegian respondents also note regional disparities in the type of rehabilitative care available. The degree of complexity of the child's need following an accident is also mentioned as a factor that could affect whether or not a child will receive rehabilitative care.

Greece is an example of a country where there are various providers of rehabilitation for children and adolescents. In select municipalities across the country rehabilitation centres operate under the governance of the Ministry of Labour, Social Security and Solidarity where services such as physiotherapy, speech therapy, and counselling are offered to children with disabilities. There are also privately run rehabilitation centres which offer support services to children, and, in addition, there are NGOs in Greece providing rehabilitation services. These support the development of children with both physical disabilities and developmental difficulties, and provide support to their families.

4.2.2 Support for a child with an ABI and their family

Supports which are available for a child in Luke's situation can be offered through local social care organisations; disability services; home care/help; children's services; and primary care. Special educational supports, various types of family support and support with mental health conditions can be offered. As outlined in Table 5, in most MOCHA countries forms of family support are offered for families like Luke's; family support includes counselling for parents and siblings and respite services. Family counselling is provided by the state and offered at a low threshold in Norway, meaning that it is easily accessible when conflicts or crises arise. It is also state-provided in other MOCHA countries such as Finland and Germany. In Ireland counselling

for parents and siblings may be available through non-governmental advocacy groups - alternatively it may have to be funded privately.

Family support throughout the MOCHA countries can also include parenting classes to learn skills for managing behaviour, information leaflets, online forums, and support from advocacy groups and family groups. The German respondent notes that in some regions in Germany initiatives for siblings of chronically ill children are hosted, while in Norway a workshop on family life for parents of children who have a disability are offered with the aim of strengthening family relationships and family life (see section 6.3.2). In Lithuania, it is noted that practical support for parents is only available through the NGO network: supports available include leaflets, advice, advocacy services, and self-support group therapy. The effect of Luke's accident on his relationships with his peers is also considered in a number of the MOCHA countries. Around half of the respondents pointed to the mental health supports available for Luke when asked about interventions supporting peer relationships, as outlined in Table 5; a distinctive approach in Hungary is noted by the respondent where community social care workers will, as best practice, visit schools to deliver sensitivity training on what their peer with complex needs is going through.

There are a number of mechanisms through which financial support is offered throughout the MOCHA countries, these include; carer's allowance; funding for equipment; transport allowance; disability allowance; personal budget; funding for training; and allowances to promote independent living and communication (see Table 5). In Estonia, for example, a higher rate of children's allowance is paid for children with complex care needs under 16 to cover the extra expenses associated with their needs, and to support the activities prescribed in a rehabilitation plan if they have one; for a child with a moderate disability the allowance entitlement is at the rate of 270% of the standard child allowance rate, and for a child with a severe disability the allowance entitlement is at a rate of 315% of the standard child allowance rate. For children with complex needs who are over 16 years old and still in education, an education allowance is paid.

In a number of the MOCHA countries a case coordinator/case manager will be in charge of coordinating Luke's care upon his discharge home from acute care. In Italy the professional in the role of case manager varies depending on the complexity of the problem; if a child's main need is rehabilitation, a rehabilitation services worker is involved; in the case of primarily social support or welfare needs, it will be a social services worker; and for an overriding health need, a health worker will be responsible. In Luke's case a social community services assistant would be involved. In around half of MOCHA countries Luke's parents would be either partly or wholly responsible for coordinating his care; where the family of a child in Luke's situation are partly responsible for his care, it will be in collaboration with a case manager, care coordinator, or other health/social care professional. In Latvia, although Luke's family are considered the primary coordinators of his care, they are supported by relevant professionals; it is primarily the family doctor who provides guidance, encouraging families to seek social assistance if necessary. Rehabilitation specialists, social workers, and social care services may also be involved. In the Netherlands meanwhile, coordination of the necessary community social care supports required before the child is discharged from a rehabilitation centre is the responsibility of a social care worker from the rehabilitation team, in some cases alongside a medical equivalent.

Table 5: Services available in European countries (scenario=ABI)

	Practical support for parents	Counselling for children	Counselling for families	Respite services	Support for peer relationships	Parenting courses
	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>
Austria	Yes	Yes	Yes^a	Yes^a	Yes^a	Yes^a
Croatia	*	*	*	*	*	*
Cyprus	Not available ^a	Yes^a	Yes^a	Not available ^a	Yes^a	Not available ^{ab}
Czech Republic	Yes^{ab}	Yes^{ab}	Yes^{ab}	Yes^{ab}	Yes^a	Yes^a
Estonia	Yes^{ab}	Yes^{ab}	Yes^a	Yes^{ab}	Yes^a	Yes
Finland	Yes	Yes^a	Yes^a	Yes	Yes^a	Yes^a
Germany	Yes	Yes	Yes	*	Yes	*
Greece	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Hungary	Yes	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Iceland	Yes^a	Yes^a	Yes^a	*	*	*
Ireland	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Italy	Yes^{ab}	Yes^{ab}	Yes^{ab}	Yes^a	Yes	Yes
Latvia	Yes^a	*	*	*	Not available ^a	Other (may be provided by an NGO) ^a
Lithuania	Yes	Yes	Yes	Not available ^a	Not available ^a	Yes
Malta	*	*	*	*	*	*
Netherlands	Yes^{ab}	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Norway	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Poland	Yes^{ab}	Yes^{ab}	Yes^{ab}	Not available ^{ab}	Yes^{ab}	Yes^{ab}
Portugal	*	*	*	*	*	*
Romania	Yes^a	Yes^a	Yes^a	Not available ^a	Yes^a	Yes^a
Slovakia	Yes^a	Yes^a	Yes^a	Yes^a	Not available	Other (Sometimes) ^a
Spain	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a	Yes^a
Sweden	Yes^{ab}	Yes^{ab}	Yes^{ab}	Yes^{ab}	Rarely available ^a	Yes^a
UK (England)	Yes^{ab}	Yes^{ab}	Yes	Yes^{ab}	Yes^{ab}	Yes

^aCountry agent response ^b Supporting policy documentation ^c Supporting research literature ^d Other external information sources * Insufficient information provided

Table 5 (cont.)

	Financial support Disability allowance (DA)	Financial support Carer allowance (CA)	Financial support Equipment (Equ) Travel allowance(TA) Education (Edu)
	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>	<i>Yes/No/Other</i>
Austria	No ^a	Yes ^a	No ^a
Croatia	Yes ^{ab}	Yes ^{ab}	No ^a
Cyprus	No ^a	Yes ^{ab}	Equ ^{ab}
Czech Republic	Yes ^{ab}	No ^a	No ^a
Estonia	Yes ^{ab}	Yes ^{ab}	Edu, TA ^{ab}
Finland	Yes ^{ab}	Yes ^{ab}	Equ ^{ab}
Germany	No ^a	Yes ^a	No ^a
Greece	Yes ^{ab}	No ^a	No ^a
Hungary	<i>None specified</i>	No ^a	No ^a
Iceland	No ^a	Yes ^{ab}	No ^a
Ireland	Yes ^{ab}	Yes ^{ab}	No ^a
Italy	No ^a	Yes ^{ab}	No ^a
Latvia	<i>Not available</i> ^a	No ^a	No ^a
Lithuania	Yes ^{ab}	No ^a	No ^a
Malta	*	*	*
Netherlands	Yes (personal care budget) ^{ab}	No ^a	No ^a
Norway	No ^a	Yes ^{ab}	Other (training allowances) ^{ab}
Poland	Yes ^{ab}	Yes ^{ab}	Equ, Edu ^{ab}
Portugal	*	*	*
Romania	Yes ^{ab}	Yes ^{ab}	No ^a
Slovakia	No ^a	Yes ^{ab}	No ^a
Spain	No ^a	Yes ^{ab}	No ^a
Sweden	No ^a	Yes ^{ab}	No ^a
UK (England)	Yes (personal care budget) ^{ab}	No ^a	No ^a

^a Country agent response ^b Supporting policy documentation ^c Supporting research literature ^d Other external information sources * Insufficient information provided

Summary of case scenario: support for a child with an ABI

- Rehabilitative care is available in most MOCHA countries; regional variations in access to rehabilitation care are notable with those living in rural areas at a disadvantage.
- Family supports which are available in many MOCHA countries include; practical support for parents; various types of financial support; counselling for families; respite services; and parenting courses. In addition, support for the child to have peer relationships is available in many MOCHA countries.
- In around half of MOCHA countries a care coordinator will be available to coordinate the child's care upon their return to the community; otherwise their parents may have to take on this role, either alone or in cooperation with a healthcare professional.

Chapter 5 Integration of Primary Care and Social Care for children with Complex Care Needs in European Countries

5.1 Introduction

In this Chapter, the framework of analysis is the horizontal integration of primary care and social care. Integration of primary and social care at the organisational level and the service level will be looked at specifically. Recent approaches to integration, and challenges to integration within the MOCHA countries will also be addressed.

5.2 Overview of integration

In most MOCHA countries, primary and social care services are the responsibilities of different bodies; in many of these cases legal or policy frameworks specify that primary and social care should coordinate and how they will do so (this is the case in thirteen MOCHA countries: Austria, Croatia, Czech Republic, Estonia, Greece, Italy, Latvia, Norway, the Netherlands, Portugal, Romania, Spain, and the UK (England)). In some cases both legal and policy documents are in place which link primary and social care, where legal documents outline the necessity of coordination, and policy documents provide guidance on how this will happen in practice. However in other cases legal frameworks are pointed to without mention of relevant policy frameworks¹⁸. In Croatia for example it is stated that the relevant laws (Law on Social Care, Law on Health Care, Law on Mandatory Health Insurance and all the relevant acts) are ‘mutually referring [to each other]’, but a policy document is not mentioned by the respondent. There are large variations in the type of formal links that exist; within the MOCHA countries there are examples of various types of organisational and service-level integration.

5.3 Organisational level integration

Organisational-level integration is where organisations are formally brought together through, for example, mergers (an example of real integration), or coordinated networks (an example of virtual integration). As Figure 2 shows, in both Finland and Ireland, a single entity is reported as responsible for both primary and social care provision¹⁹. In Finland, it is planned that from the beginning of 2019 newly-developed counties will be in charge of the implementation of both primary and social care, while in Ireland the Health Service Executive is in charge of both primary and social care implementation. The Irish respondent notes however that despite primary and social care both being provided by the same agency, in practice links between these services are informal and haven’t been properly integrated²⁰; the Health Service Executive is currently configuring community-based Children’s Disability Network Teams which are expected to provide care to those children with the most complex needs²¹. These teams will provide integrated care based on needs rather than diagnosis for children with complex needs and their families regardless of the child’s disability (whether intellectual or physical) (HSE, 2016). In Ireland, as in some of the other MOCHA countries, it is envisioned that children will

¹⁸ Croatia, Finland, Italy, Norway, Spain and the UK (England) specify a legal and policy framework; Austria, Estonia and the Netherlands specify a policy framework only; and the Czech Republic, Greece, Latvia and Portugal specify a legal framework only.

¹⁹ Northern Ireland (as part of the United Kingdom) also has a single entity in charge of both primary and social care provision. Our data for this task describes the system in England, rather than all four UK countries - thus we have omitted an explanation of the Northern Irish system.

²⁰ Thus, showing the importance of facilitating integration at more than one level.

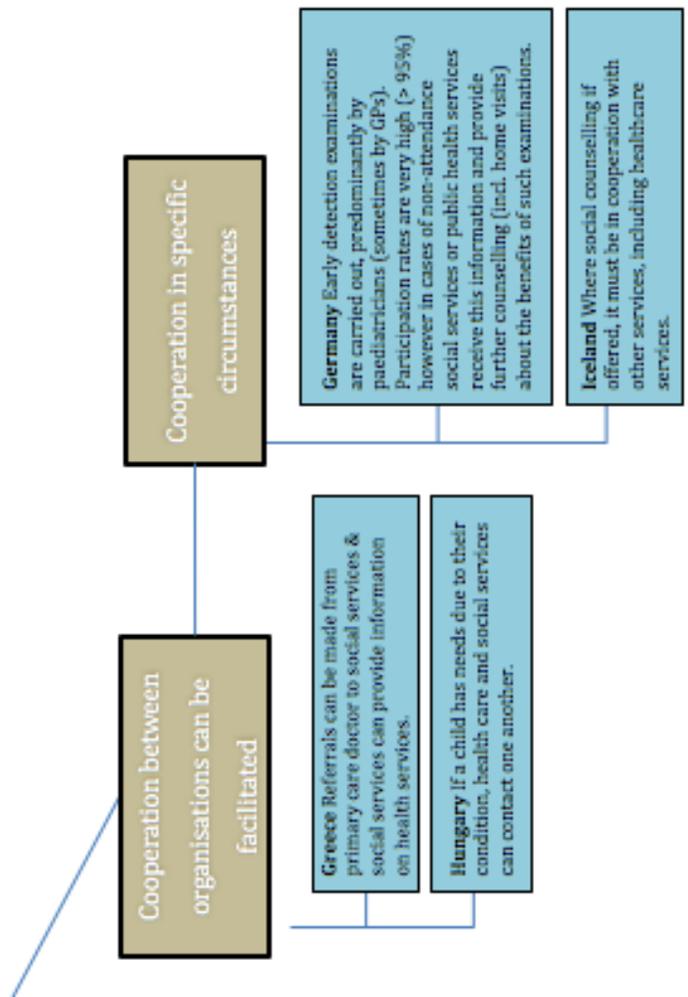
²¹ Services vary geographically and are at varying stages of configuration.

access different avenues of care depending on how complex their needs are (NDA, 2015) and it is expected that children with less complex needs will be treated through multi-disciplinary local primary care services.²²

As shown in Figure 2, alongside the MOCHA countries in which there are examples of real integration, there are also examples of virtual integration where coordination between primary care and the organisations responsible for providing social care is arranged either through networks or, more informally, through arrangements for coordination (instances of virtual integration are reported in Croatia, Cyprus, Estonia, Italy, Romania and the UK (England)). In Estonia, for instance, it is reported that municipalities and cities have their own social workers/systems; contact with primary health care doctors and nurses will start when a child is born and disabled children will receive a lot of support.

As Figure 2 shows, in some cases networks have not been established as such, but channels of communication do exist and will be utilised either as necessary, or in specific circumstances. In Greece, for example, it is noted that GPs can refer service users to social services, and social services can provide information on health services, while in Iceland the respondent does not specify a strong link between the two but notes that when social counselling is offered it must be in conjunction with healthcare services. Of the countries where respondents did not refer to a legal or policy framework, or where there is only a weak framework to link primary and social care (Cyprus, Germany, Hungary, Iceland, Lithuania, Malta, Poland, Slovakia, Sweden), a number of respondents nevertheless refer to links between organisations; in Cyprus, for example, the respondent notes that health visitors and the mother and child health centres cooperate with local authorities, voluntary and non-profit organizations, as well as government ministries.

²² Children with delays in development may have their needs met by such services which include a public health nurse, community speech and language therapy, family doctor, community physiotherapy etc.



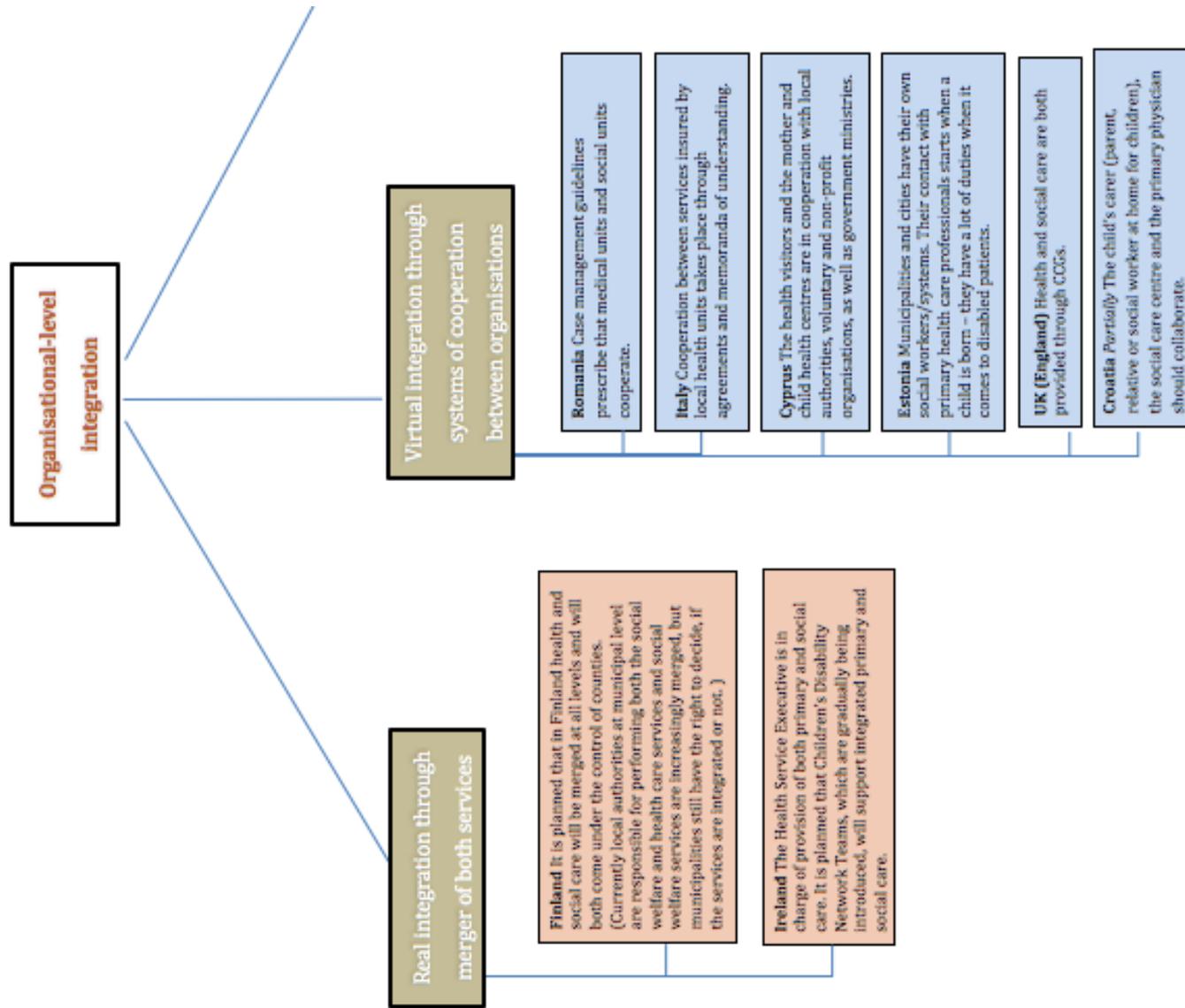


Figure 2: Organisational level integration of primary and social care

5.4 Service level integration

5.4.1 Co-location

Service-level integration is where the provision of services is integrated at an organisational level, an example being through a team of multidisciplinary professionals' (Lewis *et al.*, 2010:12). As Figure 3 displays, co-location of primary and social care professionals occurs in a number of MOCHA countries, and can occur in the primary care setting or the rehabilitation setting. Multidisciplinary primary care in one location can consist of a social worker within a multidisciplinary primary health care team; this happens in Spain - where the respondent refers to the social worker as a linkage professional, and in some instances in Sweden²³. In Lithuania, the Netherlands and Sweden multidisciplinary rehabilitative care in one location is offered. In Sweden there are 29 centres called *habilitation* centres across the country which provide rehabilitative care; these offer a range of health and social care services including physiotherapy, speech therapy, psychology, parent support and social worker services.

5.4.2 Care coordination

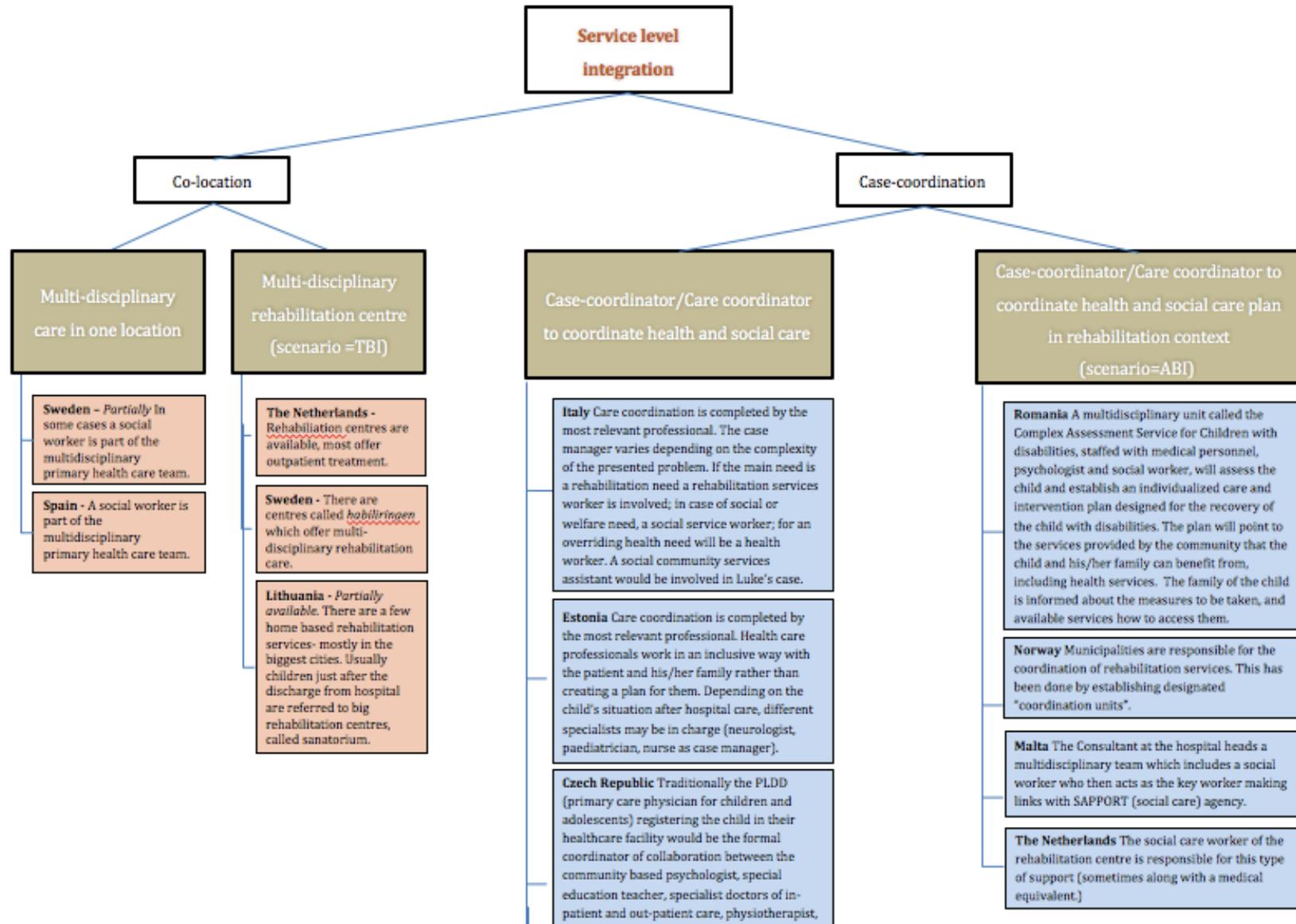
Care coordination/case management of the primary and social care needs of a service user is another common approach throughout the MOCHA countries. Coordination of service provision in the community by a health or social care professional is common with a number of MOCHA countries adopting a care coordinator or case management approach. This professional may be a primary care professional (as in the Czech Republic and Ireland) or whichever health or social care professional is thought to be the most relevant considering the needs of the child (as in Estonia and Italy). In Austria an assessment coordinator from the district administrative authority will cooperate with primary care and social care experts. Together they will decide which interventions, and what extent of care a child needs and will link with the available support services (linked are parents, supports at school (school assistance), all kind of therapy supports, the Child and Youth Competence centres, mobile services, and insurance institutions.) The District Administration Authority and social services use a common database which shows which services are available under the relevant insurance type and where. Care coordination is offered post-rehabilitation in some countries; coordination of care may be provided by a professional attached to a rehabilitation centre (as in the Netherlands), or a social worker attached to a hospital - as in Malta where the social worker will make the necessary links with the SAPPOR social care agency.

In some countries a case manager is typically only available when the needs of the child are assessed as high or severe; as discussed in the previous Chapter, in a number of countries it is the parents of a child with complex needs who will act as the coordinator of care. Cyprus is one of the countries which does not offer case coordination; the parents of a child with complex care needs or a child with disabilities would have to take on this role themselves by getting in contact with the three main government agencies and the services that coordinate social supports.²⁴ In the Netherlands, coordination of care by parents is one of two options for families with a child with complex needs. The Child and Youth Act (2015) states that local municipalities are responsible that their policy promotes effective and efficient cooperation between

²³ It is noted that in Sweden linkage professionals are more often found in secondary care.

²⁴ The Department for Social Inclusion of Persons with Disabilities, the Department of Social Welfare and Mental Health Services.

professional institutions. After a parent indicates what help their child needs, the municipality decides whether to grant it and if help is granted it will be in one of two ways, a) a PGB (personal budget), where a parent receives a set amount of money to buy/arrange the help the child needs, and they are then responsible for coordinating the care themselves, or, b) personalised care, whereby a parent relies on the municipality to arrange the care for their child. In this case everything is arranged and funded by the municipality, and the municipality decide who provides the care (the majority of care is provided by NGOs).



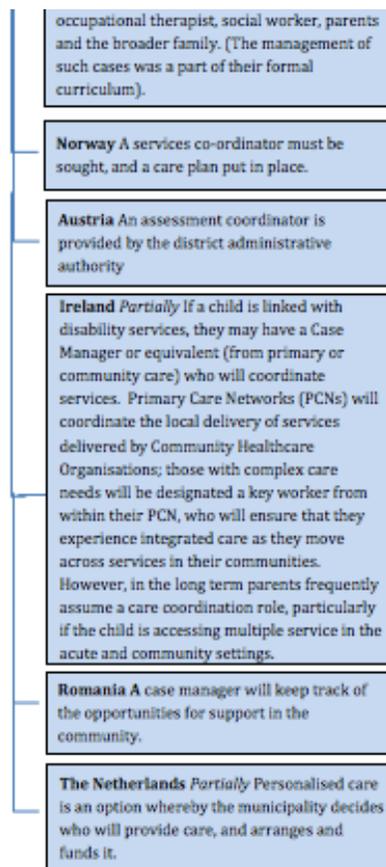


Figure 3: Service level integration of primary and social care

5.5 Recent efforts to provide better integration of care within MOCHA countries

At present, some of the MOCHA countries are planning changes in the delivery of their primary and social care services. Both Finland and England (as a part of the United Kingdom) are notable as they are currently placing great emphasis on achieving more comprehensive systems of integration. In Finland this will be achieved through the creation of autonomous counties which will be responsible for both primary and social care provision (as opposed to being under control of the lower municipal-level where they are organised at present). This is an example of real integration where primary and social care services will be brought together at all levels and will come into effect from the beginning of 2019.

In England (as a part of the United Kingdom) meanwhile, the emphasis is on increasing the effectiveness of coordination of care through virtual integration with the creation of networks. The move toward integration across all primary and social care was established under the Health and Social Care Act 2012 through which clinical commissioning groups (CCGs) were established²⁵. The policy aims regarding integration are set out as part of the Five Year Forward View; the emphasis is on coordination of primary and social care at a service level. CCGs will have influence and control over the NHS budget for their local area, and will commission services from primary to specialised care. (Less extensive changes/laws have recently come into effect in other countries, for example, in Romania which has recently brought into effect a law that specifies the manner in which the social and health sectors should coordinate care for children and adolescents with disabilities/and or special educational needs).

5.6 Challenges in the pursuit of integrated care

As noted previously, in many European countries power is decentralised; in some, central governments have delegated power to regional authorities (ranging from organisational power, to some legislative power), while in others a federal state operates with semi-independent regional governments. This has resulted in the governance of primary care and social care occurring at different levels in some MOCHA countries. Unsurprisingly, this can be problematic for the integration of primary and social care. In Latvia, for example, the respondent notes that the Ministry of Health looks after public health, and therefore family doctors are contracted with the Ministry, while social assistance and services are the responsibility of the municipalities; therefore while the policy framework does stipulate coordination between primary and social care, it is noted by the respondent that in practice social care is mostly separate - a situation which has come about partly due to this separation of primary care and social care governance. Similarly in Sweden, social services are run by the municipality and health care by the counties - therefore a legal or policy framework for the integration of primary and social care may be a difficult task to achieve.

²⁵ In terms of adult social care, the 2014 Care Act meant that local authorities must integrate adult health and social care; an ongoing initiative is the Better Care Fund which seeks to enable the joining together of health and care services at a regional level through a merging of funding. Under this scheme regional authorities, supported by a national support programme, are free to pursue integration strategies of their choosing as long as certain goals are met, and different integration strategies are currently on trial within different regions. Importantly, local governments have the opportunity to integrate other services such as housing, planning, skills, justice, and transport if they see fit.

In Germany meanwhile, there is a strong sectoral divide between primary care and social services and only a weak legal or policy framework aimed at integrating primary care and social care exists. The German respondent points out that this question is complicated by the fact that 85% of health care is provided by statutory health insurance (in contrast to tax-funded health services). While work in networks is of increasing importance in Germany, data protection laws restrict the integration of primary health services and social care services (provided in the form of state services) as the patient's consent is required to request an exchange of information between the two. (This is in contrast to Estonia where a strong informational link between primary care and social care has been established. The Social Insurance Board can request a person's health records from the Health Information System, or information from the doctor responsible for the care of a children with complex care needs, through submitting an electronic form – an example of functional integration as described in Figure 1.)

Although the respondent from Cyprus pointed to cooperative practices, as outlined in Figure 2, problems preventing further integration are also noted. These include 'fragmentation of rehabilitation services, lack of multidisciplinary treatment, limited social welfare services, and lack of coordination and continuity of care for persons with disabilities.' In section 3.3.1 of this report it was noted that social care is often provided by NGOs, and sometimes by commercial providers. This has the potential to be a challenge in terms of integrated care as social care provision could potentially be more fragmented in some instances, and thus integration with primary care more difficult to facilitate.

An additional challenge concerns the use of services at the correct level of need. For example, although the UK has well-developed primary care and social care services, in some cases children and families are not accessing social care support at a level that best matches their need but are receiving more specialised care than is necessary. This can occur when a child's needs would best be met by universal or targeted services in the community, but they are instead referred to social services. In this instance reasons for this dis-accord can include a lack of coordination of primary and social care services and a lack of awareness on the part of families and the wide range of professionals they will encounter when navigating services - an initiative which aims to address this issue is outlined in section 6.3.1.

Summary of integration of primary care and social care for children with complex care needs in European countries

- A difficulty when it comes to integration is that in some MOCHA countries primary care and social care are governed at different levels (where, for example, primary care is governed on a state-wide level, while social care governance is decentralised.)
- Coordination of both services is often pursued through coordinating laws and/or policies and many MOCHA countries have frameworks in place specifying how primary and social care should be linked (the degree of linkage specified varies considerably).
- These linkages may be through coordinating practices at the service level, such as multidisciplinary care in one location, or care coordination, or at the organisational level, such as through the creation of a network, or a merger of primary and social care services.

Chapter 6 Notable practices across MOCHA countries

6.1 Introduction

In gathering the data from the countries participating in this study it became evident that some of the challenges in providing effective social care support have been recognised and responded to within some MOCHA countries. Some of these practices are included in other sections of this report - of particular note is one of the most common solution to integrating primary and social care: the provision of a care coordinator. (Other initiatives not detailed include an effort to improve information provision through the development of a handbook for persons with disabilities which has been produced in the Czech Republic). While undoubtedly there are many notable frameworks/practices in place throughout the MOCHA countries, in this Chapter three in particular which have emerged during this study are explored (one in detail, and two in brief). These are frameworks/practices which may provide better outcomes for children with complex care needs and their families; the first shows potential to ensure an 'integrated' response to children with complex care needs who are in need of social care support, and those who are in need of safeguarding; the second is an initiative which seeks to ensure that children's complex care needs are met at the most appropriate level of care; and, the third, an example of provision of social care support for parents of a child with complex needs.

6.2 Overview of the *Framework for the Assessment of Children in Need and their Families*

Any assessment framework that puts the child at the centre, and that recognises both health and social care needs as well as the needs of parents/carers, seems consistent with emerging principles from both the EU Commission and the WHO. One such framework that has gathered some traction across a number of EU countries is the *Framework for the Assessment of Children in Need and their Families* (Department of Health, England *et al.*, 2000) (known as the Assessment Framework, or AF). Tools based on this framework are used in the MOCHA countries of Denmark, France, Finland, Hungary, Ireland, Sweden, the UK (where frameworks are used in all four countries) and Ukraine²⁶; they are used with children, including those with complex needs, where it is felt there is a need for intervention from social services in order to ensure that all of the child's needs are met and/or where it is felt there may be a child protection concern, as well as with looked after children in some cases.

The AF was designed as guidance for local authority social services in England (as part of the UK) to promote the wellbeing of children in need by supporting families through the provision of the necessary services. The framework hinges on a conceptual model designed to provide an understanding of a child's world from an ecological perspective (based on the work of Urie Bronfenbrenner, 1986) in order to enable a child-centric assessment of the needs of the child and the family (The work of Bronfenbrenner is of great relevance to the MOCHA project as a whole as Bronfenbrenner's ecological model of determinants of health is included in the MOCHA Conceptual Framework of a Model outlined in Work Package 1 (Blair *et al.*, 2016;137); and was

²⁶ The framework has been used in original or adapted form, or has been recommended for use, in 15 countries (Léveillé and Chamberland, 2010). (Léveillé and Chamberland point out the adaptability of the framework in different contexts internationally but it should be noted that the approach is provided for use by the UK government through a license which controls how much an adapted framework can differ from the original.)

designed to be appropriate for use with children with disabilities (the definition of a child in need is provided by the English Children’s Act 1989, a definition which includes children with disabilities).

The principles behind the framework can be summed up as;

- **Allowing children to participate in decisions about their lives;** children should be encouraged to take part in the assessment of their needs
- **Providing a child-centric means of systematic assessment which thus ensures a uniform approach;** In assessing the child’s life from an ecological perspective the AF takes into account their developmental needs, parent/carer capacity to respond appropriately to those needs, and family and environmental factors which have an impact on the family - this information is represented in Figure 4 below.
- **Considering the needs of the family in conjunction with those of the child;** guidance on the framework emphasises that this is the most effective way to provide help to a family
- **Facilitating provision of a joined-up approach where services coordinate and communicate;** there should be effective collaboration between staff from different disciplines and agencies. A common language is required in order to understand the needs of children (Department of Health, England, 2000).



(Department of Health, 2000)

Figure 4: Conceptual framework behind the Assessment Framework

6.2.1 Adaptions of the Assessment Framework

Currently in England (as a part of the United Kingdom), models based on the AF are among the tools currently used with children, including those with complex needs, in need of support to achieve their optimal wellbeing. In a number of the other European countries where it is in use it, it is used in child protection cases only, and in some countries it is used exclusively with

looked after children (see Table 6 below). Uniquely, in Ireland it has been adapted into a voluntary model to provide coordinated support across services to children and families who are vulnerable but do not require social work intervention (in a similar manner to the regional innovation, the Disability Network Forum, in Birmingham, UK described in the next section). For a detailed account of how the framework is utilised in practice in two of these jurisdictions, see Appendix C where its adaptation for use in Scotland (as part of the United Kingdom) and in Sweden is outlined.

Table 6: Adaptation of the Assessment Framework across Europe²⁷

Country	Use of AF-based model for children with no identified additional needs	Use of AF-based model for children in need of support	Use of AF-based model for assessments of children and families considered at risk (child protection concern)	Use of AF-based model for looked after children	Recommended by European Commission for use with children placed in orphanages
United Kingdom		✓ (except NI)		✓	
Ireland		✓ (on voluntary basis)			
Sweden		✓	✓		
Ukraine				✓	
France			✓		
Denmark	✓				
Finland				✓	
Hungary	✓				✓
Greece					✓
Poland					✓
Czech Republic					✓
Romania					✓

(Information on the UK, Ukraine, France, Denmark, Finland, Hungary, Greece, Poland, Czech Republic and Romania from Léveillé and Chamberlain, 2010;934)

6.2.2 Use of models based on the Assessment Framework with children with complex needs

In an evaluation of the AF, Marchant supports its use with children with complex care needs believing that the principles behind it are especially useful when working with these children. Marchant emphasises the ‘ecological and empowerment’ models behind the framework (Marchant, 2001); considering that their lives are likely to involve many decisions about their care and their lifestyle, it can be expected that participation in such decisions is of great importance for children with complex care needs and there is a growing body of evidence showing both children’s competence and the relevance of their experience in health and care-related decision-making (see Franklin and Sloper, 2008; Franklin and Sloper, 2006; Mitchell and

²⁷ According to Léveillé and Chamberlain the AF has also been adapted for use in Norway but has not been implemented yet (2010).

Sloper, 2011); similarly, the literature clearly shows the need for joined-up service provision in order to adequately meet the varied range of needs of children with complex care needs. The ecological focus of the AF could prove useful as a way to provide focus to multi-agency working. (In the past multi-agency working for children with disabilities has been found to increase the effectiveness of health care provision, but to be not as effective at meeting the wider needs of this group of children and their families, in particular their social and emotional needs (Abbott *et al.*, 2005).) In Table 7 barriers and facilitators to the use of AF-based models in the UK, where models have been used with children in need of support, are outlined.

Table 7: Barriers and Facilitators to use of models based on the Assessment Framework with children with complex needs

<i>Facilitators</i>	<i>Barriers</i>
<ul style="list-style-type: none"> • <i>Ensuring to facilitate communication (through the use of interpreters or facilitators, communication books, body language, and electronic communication aids, for example).</i> 	<ul style="list-style-type: none"> • <i>One-size-fits-all approach</i>
<ul style="list-style-type: none"> • <i>Training for working with children with complex care needs and for working with new policies</i> 	<ul style="list-style-type: none"> • <i>Communication</i>
<ul style="list-style-type: none"> • <i>Practitioners thinking about their own experience of disability and what preconceptions they may have can enable them to complete a more successful assessment (Marchant, 2001).</i> 	<ul style="list-style-type: none"> • <i>Problems around the need to assess parenting capacity</i>
<ul style="list-style-type: none"> • <i>Clear signalling that within a service that it's inclusive of all children – eg., having toys, books and other resources that are suitable for all children (Marchant, 2001).</i> 	<ul style="list-style-type: none"> • <i>Needs to be used only where necessary as could be overly intrusive when only a basic service is requested</i>
<ul style="list-style-type: none"> • <i>Advocacy services could potentially be an enabler for successful implementation of the AF.</i> 	

(Marchant, 2001; Mitchell and Sloper, 2008; Wonnacott *et al.*, 2013, Cleaver, 2004).

6.3 Other notable initiatives in the MOCHA countries

6.3.1 Ensuring appropriate use of services

In section 5.6 of this report the fact that in a few MOCHA countries there are children with complex needs accessing specialist services when they could be more appropriately helped in universal or targeted services was referred to; the overuse, underuse and misuse of services is something that is also flagged by the WHO (2013). An example of a recent initiative to address

this issue is the Disability Network Forum in Birmingham, UK²⁸. This network consists of a multi-agency group where professionals from health and social care work together to look at individual cases where the progress of a child on their Education, Health and Care plan²⁹ is felt to have stagnated, but an intervention by social services is not believed to be warranted. After a solution-focused assessment families receive provision of relevant information on whether specialist social services or universal targeted services are most appropriate to meet the needs of their child. This has been an effective model in achieving a response to children's needs as well as potentially reducing demand of services for children with more complex needs.

6.3.2 Provision of parenting support

An initiative in Norway which aims to meet the informational and support needs of parents of a child with a complex care needs is a weekend long parenting course. The course, entitled *Hva med oss?* or *What about us?*, is offered by the Directorate for Children, Youth and Family Affairs (Bufdir) to parents of children with complex needs at a low deductible cost. The courses cover family life, addressing topics such as communication, teamwork, sibling relationships, complex emotions, and family life generally. The purpose is to strengthen relationships and family life, and provide a chance to swap experiences, to reflect and to celebrate. It is also noted that for parents of a child with complex care needs, meeting other parents in a similar situation can be of great help.

Summary of overview of potential enabling practices

- Within the MOCHA countries there are example of practices aiming to enable the provision of effective social care support.
- Examples presented in this report are
 - a model which aims to meet the interconnected health and social care needs of children with complex care needs and their families;
 - an initiative seeking to ensure that children's complex care needs are met at the most appropriate level of care; and
 - an example of provision of support for parents of a child with complex needs.

²⁸ A report on the work of the Disability Network Forum is forthcoming

²⁹ An EHCP is a legal document which has similar statutory power to a statement of special educational needs, but which describes a child or young person's health and care needs where these are significant. At school, most children will make progress with the support of their class teacher through the school's arrangements known as SEN Support.

Chapter 7 Conclusion

For many children, it is their parents or carers who are responsible for meeting their social care needs; in many MOCHA countries they may be the ones navigating the myriad of state organisations in order to access the additional supports that they or their child require. Although there is an increasing emphasis throughout European countries on integrating primary and social care, when mapping social care services two things become clear; firstly, that defining how social care is delivered in different cultures and contexts is a challenge as social care needs are varied and interwoven with other needs, such as those of health and education, and thus are not necessarily met by social care services; and secondly that the role played by external organisations of various types in the provision of social care throughout Europe is considerable - this represents fragmentation of social care provision and must surely present a challenge for coordination between primary care and social care as state and non-state actors must cooperate. To ensure effective coordination it might be useful if there was a common understanding of the social care needs of children with complex care needs. The concepts underpinning the Framework for Assessment covered in Chapter 6 may prove useful in this regard.

All the MOCHA countries have legislation for providing social care support to children with complex care needs. It is evident that the delivery of the kinds of support needed may be through a complex array of organisational structures. It is difficult to know how easy it is to access support and whether funding or insurance coverage is sufficient to meet the needs of all, or if there will tend to be some form of 'rationing'³⁰ based on prioritising the level of need. Something that is evident is that most countries have some element of regional variation in the delivery of social care - in particular living in a rural area can disadvantage children with complex care needs and their families (this is something that is reflected in a 2015 OECD report on integrated social services for vulnerable groups). It is clear that existing policies must be facilitated in practice throughout each country in order to ensure equity of opportunity.

Arrangements for coordination between primary care and social care are common to a number of the MOCHA countries. As noted, some countries are investing significant funding in further integrating health and social care systems. In Finland real integration is prioritised with the creation of a model where systems will be more fully integrated by coming under the responsibility of one organisation.³¹ It should be kept in mind however that Lewis *et al.* (2010) note that full organisational integration is not necessarily optimal and "it may be that a care user's needs are better served through less organisational integration and more opportunity for choice and personalisation of care across a range of alternative providers that is well coordinated" (2010; 12). Leutz is of a similar opinion for a different reason; he asserts that coordination may be a better strategy when striving to meet the needs of the whole population (1999).

³⁰ Rationing care limits a patients access to care

³¹ The difficulties inherent in creating such a system have been proven in the real-life example of the Better Care Fund in the UK (England) which has recently been evaluated by the National Audit Office (NAO). Disability Rights UK notes that the NAO assessment warns that "progress with integration of health and social care has been slower and less successful than envisaged and has not delivered all of the expected benefits for patients, the NHS or local authorities" (Disability Rights UK, 2017).

There are a few other examples of planned or recent changes to promote primary and social care integration throughout the MOCHA countries, which point to a marked recognition of the importance of linking primary health care with social care. This recognition holds true on a wider scale with the WHO European region also placing great emphasis on the importance of intersectoral approaches in its Health 2020 policy framework (a framework which the WHO considers to complement the EU's Europe 2020 policy framework³²). This policy works to 'promote and strengthen the sharing of good practices, to apply intersectoral approaches, and to reach consensus on working collaboratively across the health, social and education sectors to reduce inequalities among children and adolescents' (WHO, 2016)³³. It is important to consider how primary and social care integration sits within the delivery of people-centred care across the health system as a whole and the WHO has recently provided recommendations on whole systems people-centred care, offering a framework for shaping integrated services (WHO, 2015)³⁴. What the WHO outlines is an ambitious plan to achieve universal health coverage and people centred care, advocating for a consideration of integrated care at a whole systems level. In an EU-context, there is much interest in the concept of co-created care, where service users and healthcare professionals work in partnership; it seems clear that the service user will have more of a say in their own healthcare in future.

For an intersectoral approach to be successful, it is important that parents and families are provided sufficient information on what supports are most appropriate for their child, be they specialist social care systems or universal services. The AF seems to have great potential for use in terms of specialist service provision for children with complex care needs where there is concern that their wellbeing needs are not being met, or where they are in need of safeguarding. In addition however, it may also have potential to act as a reference point when approaching the task of designing a coordinated approach to primary care and social care. In much the same way that the earlier-cited WHO report describes the creation of people-centred care as a design principle, the principles behind the AF can be thought of as a design principle when thinking about integrated care for children. Taking an ecological perspective and recognising that different needs are interdependent and should be addressed as such, as well as placing emphasis on children's participation while also considering their family's needs are valuable priorities to have when beginning to design such a system and the concepts behind this framework would be useful for any model of primary care as a way of focusing on the wider needs of children.

Finally, we can conclude that there would be benefits, not least greater equity, if a consideration of optimum social care needs included the relevant child welfare and protection issues; it is vital that consideration is paid to how professionals are trained to detect and to deal with cases of abuse when children have communication or cognitive impairments. Given the additional

³² Horizon 2020 is a part of Europe 2020

³³ These are the stated aims of a WHO conference held in Paris in December 2016. The conference had an outcome statement on promoting intersectoral and interagency action for health and well-being in the WHO European region within the sectors of health, social support and education. The conference produced a draft statement outlining these objectives which will be endorsed by the WHO Regional Committee (the parliament of WHO consisting of the health ministers from all 53 member states) at its annual meeting in September 2017.

³⁴ Something which has come up in this report which may act as a barrier to such an intersectoral approach is outlined by the German respondent who points to how data protection regulations act as an obstacle to cooperation between primary and social care in Germany. Consideration of how data protection laws can best work alongside laws designed to integrate across different sectors would be of great relevance for the MOCHA countries.

vulnerability of children with complex care needs it seems critical that all countries should have in place specific legal provisions for the welfare and protection of these children.

This work has demonstrated the need for further research to take place outside of the scope of the MOCHA project. This should now be undertaken to help complete the picture of social care throughout Europe, and includes:

- assessment of the accessibility of the social care supports which are in the community;
- examination of the referral processes from primary care to external organisations providing social care;
- examination of similarities in the facilitators and barriers to the integration of primary care and social care for children with complex care needs in European countries;
- examination of skills/training for social care professionals;
- options for multidisciplinary training of primary and social care professionals; and
- assessment of the impact of resource rationing on meeting the social care needs of children with complex care needs.

7.1.1 Limitations

In this report the tracer condition of an ABI was used in order to gather comparable data across the MOCHA countries where information was gathered on what supports would be available to support a child with an ABI and their family. The limitations of looking at only one tracer condition however must be acknowledged. In most MOCHA countries, the location where primary care/social care is received will vary depending on the needs of the child (for some children, for example, the majority of care will be in the home) and the extent of integrated care that is required for the child and family will vary depending on need – for example, some children with a complex care need and their families will benefit from a care coordinator, while for others where the nature of that need is different, information provision, for example from a GP, on which services are available would be what is most helpful. In order to study this issue in more depth, comparable data on support for a range of conditions requiring different levels and types of support would be beneficial.

7.2 Conclusions

This work of this report sits within the wider work of Work Package 2, which seeks to outline safe and efficient interfaces of models of primary health care with secondary, social and complex care in the EU and EEA. This is significant for being the first mapping exercise of this sort to be undertaken. This report provides an overview of social care support for children with complex care needs in European countries, and describes the primary care and social care interface. In addition, as equity in child protection for children with complex care needs is identified as an area which must be addressed in order to provide optimum social care support for this population, the care pathway of children with complex care needs who are at risk and require safeguarding is also examined.

The social care needs of children with complex care needs may cut across a number of different government agencies (for example, those dealing with education, in-home support and financial support or social welfare). There is no country where the broad range of relevant services for this population come under one organisational structure, however all countries do have forms of social care provision for children with complex care needs. Driven by a growing body of

evidence that suggests integrated care can provide a higher quality service and a more positive user experience, at a lower cost, it is something that is pursued in many MOCHA countries; while there are pronounced differences in the level of social care provision across MOCHA countries, integrated primary and social care provision is an area where there is commonality between a number of countries in that there is often an emphasis on the integration of social care within the existing health care structure, rather than an attempt to merge the two. The reason behind this however may in some cases be that coordination is used as the means of smoothing over significant lack of fit - often caused by the fact that primary care and social care are not coterminous in governance, organisation or funding. Following on from the work presented in this report, a model of complex care will be developed in collaboration with Work Package 2 team members, which will inform the work of Work Package 9 on the appraisal of child primary health care models.

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Appendices

Appendix A: Country agent questionnaire



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

WP2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care

Task 3: The Social Care Interface

The aim of this task is to understand the interface between social care and primary health care for children with complex health needs. This questionnaire hopes to generate up-to-date evidence on the comprehensiveness, coordination, and continuity of social care support for children with complex health needs across Europe.

The questionnaire is divided into two sections. The first section asks about the legal and policy framework underpinning the provision of social care services for children with complex health care needs. We also include a number of questions on the structure of social care services. The second section uses a case scenario/ vignette which portrays the experiences of an adolescent who sustained a traumatic brain injury (ABI). The accompanying questions seek to map out the type of social care support that would be available in the community and the typical social care pathway for a child with complex needs such as ABI.

We suggest that social care or social work experts with knowledge of the provision of social services for children with complex health needs and/or disabilities would be best placed to answer these questions. This may be a professor of child and family social work based in an academic or research institute, or a senior social worker involved in the provision of child and family services in the community, primary health care setting, or a rehabilitation centre.

Please answer as many questions as possible and where relevant please provide links to any policies or guidelines.

Thank you for taking the time to complete this questionnaire.

Please send all answers to Denise Alexander by **24th June 2016**.

Glossary

Acute care refers to the secondary/tertiary care centre from which a child may be admitted or discharged to the community/primary care service. It includes “the health system components,

or care delivery platforms, used to treat sudden, often unexpected, urgent or emergent episodes of injury and illness that can lead to death or disability without rapid intervention. The term *acute care* encompasses a range of clinical health-care functions, including emergency medicine, trauma care, pre-hospital emergency care, acute care surgery, critical care, urgent care and short-term inpatient stabilization” (Hirshon *et al.*, 2013 p. 387)

Allied health care professionals refers to those who provide preventative or rehabilitation services such as physiotherapists, occupational therapists, dieticians or speech and language therapists. Allied health care professionals work in a wide variety of settings including the acute, post-acute, and primary health care settings. They typically work closely with social care professionals (see definition below) in primary health care or specialist services.

Alternative care is the care ‘provided for children by caregivers who are not their biological parents. This care may take the form of informal or formal care. Alternative care may be kinship care; foster care; other forms of family-based or family-like care placements; residential care; or supervised independent living arrangements for children’ (Interagency Working Group on Unaccompanied and Separated Children, 2013 p.9)

A **child** refers to anyone under the age of 18 years old (UNCRC, 1992).

Children with complex physical health care needs have substantial care needs as a result of one or more congenital, acquired or chronic conditions, with need of access to multiple health and social support services. These children may have functional limitations which often require tailored technological assistance (Cohen *et al.* 2011, Elias & Murphy 2012). The term ‘disability’ is sometimes used to describe children with complex health care needs as long term physical and developmental impairments may be expected.

Children with complex mental health needs in the context of this task refers to children with a mental health condition that threatens or hinders an age-appropriate mental health development, that requires input from a range of health and social care professionals, and from which long-term mental health problems and/or disabilities may be expected.

A **child with a disability** refers ‘those below the age of 18 who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (European Agency for Fundamental Human Rights, 2015).

Child protection or safeguarding refers to methods aimed at preventing and responding to violence, exploitation and abuse of children (UNICEF, 2006).

Child welfare is a term which is broader than ‘child protection’ and relates to actions taken to promote the welfare of children with specific needs and is defined as including the following:

- preventing impairment of children’s health and development
- ensuring that children grow up in circumstances consistent with the provision of safe and effective care and
- taking action to enable all children to have the best outcomes (Department for Children & Families, England 2008)

Community care is defined as ‘the blend of health and social services provided to an individual or family in his/her place of residence for the purpose of promoting, maintaining or restoring health or minimizing the effects of illness and disability’ (World Health Organization, 2004, p. 16).

Care coordination may be defined as the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient’s care to

facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care (McDonald *et al.*, 2007, Schultz & McDonald 2014).

Case management is the method of assessing the needs of the child and the child's family and current caregiver, advocating for, arranging, coordinating, monitoring and following up on both direct services and referrals required to meet the child's complex needs' (Interagency Working Group on Unaccompanied and Separated Children, 2013 p.10).

Foster care is a care arrangement administered by a competent authority, whether on an emergency, short-term or long-term basis, whereby a child is placed in the domestic environment of a family who have been selected, prepared and authorised to provide such care, and are supervised and may be financially and/or non-financially supported in doing so' (Interagency Working Group on Unaccompanied and Separated Children, 2013 p.10).

Informal care is defined as any private arrangement provided in a family environment whereby the child is looked after on an ongoing or indefinite basis by relatives, friends or others in their individual capacity, on the initiative of the child, his or her parents and other people, without this arrangement having been ordered by an administrative or judicial authority or accredited body' (Roby, 2011, p. 10).

Non-government organisation generally refers to independent voluntary organisations with a humanitarian remit. NGOs include charities, non-profit organisation and foundations.

Outsourcing or sub-contracting refers to situations where the service is not provided directly by a public authority but instead is contracted to an external provider (Pittini, 2011).

'In social care, an **'outcome'** refers to an aim or objective a service user would like to achieve or need to happen – for example, continuing to live in their own home, or being able to go out and about.' (Webb, 2014, p. 4)

Post-acute care for this task refers to in-patient rehabilitation which includes care provided 'by a multi-professional team who have undergone recognised specialist training in rehabilitation, led /supported by a consultant trained (rehabilitation medicine, and other relevant specialties eg neuropsychiatry) and accredited in rehabilitation medicine (RM)' (Turner-Stoke, 2015, p. 2).

Primary health care is generally defined as first-contact, accessible, continued, comprehensive and coordinated health care provided by a single practitioner (GP/ nurse practitioner/ paediatrician) or a multidisciplinary team of professionals in a community practice (WHO 2008, Davy *et al.*, 2015)

Public authority refers to any national, state, municipality or local government agency.

Rehabilitation 'is a process of assessment, treatment and management by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the trajectory and stage of their condition' (Turner-Stoke, 2015, p. 2). Rehabilitation can take place in the acute, community or home setting.

Residential care 'is a group-living arrangement in a specially designated facility where salaried staff or volunteers ensure care on a shift basis. Residential care is an umbrella term that includes short- and long-term placements in institutions, small-group homes, places of safety for emergency care, and transit centres' (Interagency Working Group on Unaccompanied and Separated Children, 2013 p.12).

Respite care is provided by appropriately trained individual(s) for a specified period of time for children with complex needs, or individuals with disabilities, thus providing a break from

caregiving by a parent or family member. Respite care may include: day-care services; in-home respite; and residential/institutional respite (Francesca, Ana, Jérôme, & Frits, 2011).

Social care needs arise when an individual's well-being, quality of life, social inclusion, ability to live independently, fundamental rights or safety are compromised. For children with complex health care needs, 'social care needs' refers to a wide range of everyday needs such as the ability to enjoy friends and family, participate in school, engage in leisure and social activities and have a safe and happy home environment (Marchant *et al.*, 2007)

Social care services (OR personal social services AND/OR social work services)

encompass *personal or targeted* support for individuals with specific needs. 'These services can play a preventive and social cohesion role by providing customised assistance to facilitate social inclusion and safeguard fundamental rights' (European Commission 2007, p. 4). Services can provide assistance for persons facing personal challenges or crises (e.g. child abuse or neglect), support to ensure that the persons concerned are able to completely reintegrate into society (e.g. rehabilitation following a brain injury), or can encompass services to integrate persons with disabilities or long-term health problems (e.g. support to participate in community activities) (European Commission 2007).

For children with complex health care needs social care support may be accessed via child protection and welfare services, general social work/care departments, disability community services, primary health care, mental health services AND/OR specialist services for specific conditions (i.e. brain injury). Social care services can be provided directly by public authorities, non-government organisations, for profit organisations or informally by family members.

Social care professionals is used to describe persons who support an individual's physical, mental and social functioning through improved coping skills and use of social supports and community health care services. There are many different types, specialties and grades of social care professionals based on qualifications and experience (World Health Organization, 2004, p. 52). Those who practice social care are generally called social workers or social care workers but they can also include personal care assistants, support workers, advocacy workers, community workers, and outreach workers. In some countries social care workers are referred to as social pedagogue or 'éducateur spécialisé' or 'educatore sociale'. Social care professionals can specialise in children and families, medical social care (i.e. hospital based social care professionals), palliative or hospice care, mental health, and ageing and older people.

Social protection refers to policies and measures that support 'the standard of living of disadvantaged or vulnerable groups. Benefits may be targeted at low-income households, the elderly, disabled, sick, unemployed, or young persons. Social spending comprises cash benefits, direct in-kind provision of goods and services, and tax breaks with social purposes. To be considered "social", programmes have to involve either redistribution of resources across households or compulsory participation' <https://data.oecd.org/socialexp/social-spending.htm>

Traumatic brain injury means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance or social well-being. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behaviour; physical functions; information processing; and speech (National Dissemination Center for Children with Disabilities, 2011, <http://www.parentcenterhub.org/repository/ABI/>). **Acquired brain injury** is a broader term used to incorporate non-traumatic forms of brain injury such as stroke.

Universal social services refers to services such as transport, leisure, health and education that should be available to everyone. These are distinct from social care services as they are not dependent on assessment or eligibility.

Section 1: Social Care Policy and Organisational Context

The purpose of this section is to understand the national context within which social care services for children with complex health care needs are provided.

The term 'social care services', as outlined in the glossary, is used to cover all services that may otherwise be referred to in your country as 'personal social services', and/or 'social work services'.

Children with complex health care needs may be referred to within your countries' legal and policy framework using the broader term 'children with disabilities'. These terms can be used interchangeably in the first section of this questionnaire. Please refer to the glossary of terms for further guidance.

1.1 Legal and policy framework³⁵

Social care/ personal social services

In your country...

1. Is there a main legal or policy framework for the provision of social care services? (e.g. Social Care Act) (Please tick all that apply)

Yes, a legal framework Yes, a policy framework No (continue to q3)

If yes, please provide the name and year of this legal/ policy framework.

2. Does this legal or policy framework have a specific section on the provision of social care services for children with complex health care needs/ children with disabilities?

Yes No

If yes, please provide details of these specific entitlements.

Child protection and welfare

In your country.....

3. Is there a legal framework for child protection, safeguarding and/or welfare (e.g. Child Protection Act)?

Yes No (continue to q4)

If yes, please provide the name and details of the legal/ policy framework.

- a. Does this legal framework provide specific guidance on safeguarding and protecting children with complex health care needs/ children with disabilities from abuse and neglect?

Yes No

If yes, please provide details.

³⁵ For this task a legal framework refers to any laws (e.g. Child Care Act etc.) or legislation that governs the provision of, and entitlement to services. A policy framework refers to any strategies, actions plans or guidelines (e.g. National Children's Strategy).

b. Does the legal framework provide specific guidance on promoting the welfare of children with complex health care needs/ children with disabilities?³⁶

- Yes No

If yes, please provide details.

4. Has there been any child protection cases involving a child with complex health care needs/ child with a disability that prompted a change in your countries' policy or legal framework?

- Yes No Not applicable

If yes, please provide details.

5. Do any of the policy/legislative frameworks outlined above incorporate elements of the UN Convention on Human Rights AND/OR the UN Convention on the Rights of the Child AND/OR the UN Convention of the Rights of Persons with Disabilities?

- Yes No Not applicable

If yes, please provide details.

Integrated health and social care

6. Is there a policy or legal framework that links social care services to primary health care?

- Yes, a legal framework Yes, a policy framework No

If yes, please provide details.

Assessment frameworks

In your country....

7. Is there an agreed social care assessment framework for children with complex health care needs/ children with disabilities? (e.g. Common Assessment Framework)

- Yes No

If yes, please provide details.

1.2: Organisation of social care services for children with complex needs

In your country....

8. Is there a central authority with national coordinating role for social care services for children with complex health care needs/ children with disabilities?

- Yes, please provide the name of this national authority:
 No, it is decentralised to local, municipality or regional level
 Other, please specify:

Please provide additional details on the structure and organisation of social care services for children with complex health care needs/ children with disabilities.

³⁶ This refers to any entitlement to the provision of services that promote the welfare of children with additional needs. Children in need is defined as those who are unlikely to achieve a reasonable standard of health and development without the provision of social services. Please refer to the glossary of terms for the distinction between 'child protection' and 'child welfare'.

9. Are there formalised structures that link primary health care services to social care services for children with complex health care needs/ children with disabilities?

Yes No

Please provide details on how social care services are linked to primary health care services in your country.

10. Does the legal framework allow for outsourcing of social care services for children with complex health care needs/ children with disabilities to commercial AND/OR non-government organisations? (Please tick all that apply)

- Yes, commercial organisations (for profit)
 Yes, non-government organisations (not for profit)
 No
 Not applicable
 Other, please specify:

Please provide any additional details on the funding of social care services in your country.

Section 2: Case Scenario – Traumatic Brain Injury

The purpose of this section is to understand how social care services are provided in your country.³⁷ The aim is to find out what happens in practice when a child with complex needs requires social care supports in the community. Please consider the following two scenarios and answer all accompanying questions.

2.1: Social care planning at acute/ post-acute discharge

Luke, a 15 year old previously healthy adolescent, suffered a head injury in a skateboard accident. He did not have any spinal injury. He spends five months in post-acute inpatient care and makes good progress with regard to his physical recovery. At the point of discharge he has ongoing right-sided weakness, facial palsy and poor cognitive functioning. He is also exhibiting severe mood swings and appears depressed and anxious. His parents are worried as his discharge is being discussed. They are concerned that his outbursts towards his sister during visits have been frightening and upsetting for her. They are keen to bring Luke home but are worried about the level of supervision he will need, and his ability to return to school and interact with his peers.

Planning, sourcing and organising social care support in the community

In your country.....

11. Who is typically responsible for organising the community social care supports required for Luke and his family before he is discharged home (e.g. emotional and practical support for Luke's parents, financial support, sibling support, supports for Luke when returning to school etc.)?

- Luke's parents
 Care coordinator or case manager
 Discharge nurse
 Other, please provide details:

³⁷ This scenario is adapted from a case scenario originally developed by the task 2, WP2 team including; Dr. Maria Brenner, Prof. Philip Larkin, Dr. Jay Berry and Dr. Miriam O'Shea.

Please provide details for your answer.

12. Is there a specialised community/home based rehabilitation service where Luke would be referred to at the point of discharge?

- Yes No

If **yes**, please provide details on the structure of this service and the types of support it provides.

If **no**, please provide details on the types of services Luke would be referred to at the point of discharge (if applicable).

2.2: Social care support in the community

Six months have passed since Luke was discharged home. Luke's physical rehabilitation has went well and he returned to school three months ago. Recently Luke's parents have noticed he has become more anxious and they are finding it very difficult to manage his behaviour. His aggression towards his family has increased and this is having a negative impact on his parents' and sister's well-being. The routines of family life have changed significantly as Luke's behaviour and especially his temper can flare up while out in public, therefore, family outings have ceased. At school Luke is having trouble concentrating in class and interacting with his peers. Prior to Luke's injury both his parents worked full time, but his mother has stopped working in order to care for Luke. On a recent visit to the GP, his parents express the difficulties they are having caring for Luke and ask for assistance.

Organising and coordinating social care support

In your country...

13. Who is typically responsible for coordinating the social care supports required for Luke and his family at home and in the community?

- Luke's family
 Care coordinator or case manager
 GP/ Paediatrician
 Other, please specify:

Please provide details for your answer.

Types of social care support in the community

In your country....

14. Which type of services could Luke and his family access to support and address the needs described in the table below?

Social care need

Please list of the types of services/ supports that would be available to Luke and his family in the community.

a. Practical support and information for Luke's parents in their caring role (e.g. leaflets, advice & advocacy services etc.)

b. Financial support for Luke’s parents in their caring role (Please specify the type of entitlement e.g. Carers Benefit)	
c. Counselling and support for Luke	
d. Counselling and support for Luke’s parents	
e. Counselling and support for Luke’s sister	
f. Respite or short breaks for Luke’s family	
g. Programmes or interventions to support Luke’s peer relationships and social interactions	
h. Parenting skills for managing Luke’s behaviour	

15. Would the types of social care supports/ services described above differ if Luke had severe intellectual impairments (e.g. unable to attend school or complete daily tasks such as personal care)?

- Yes No

Please provide details for your answer.

16. Would the types of social care supports/services described above differ if Luke had a severe physical impairment (e.g. a spinal injury)?

- Yes No

Please provide details for your answer.

2.3: Child protection and alternative care system

The purpose of this section is to understand the interface between child protection services and primary health care services for children with complex health care needs. Please consider the following scenario and answer all accompanying questions.

Luke is a 15 year old boy with a traumatic brain injury.

Luke continues to have significant challenges with regard to cognitive, communication and executive functioning. As a result, he is not able to make significant decisions with regard to his own care and support needs.

Over the past number of months his mood swings have continued and he has become more violent. On two occasions Luke has been in a physical fight with his father. In addition, his mother’s mental health has significantly deteriorated and she is having difficulty coping and caring for Luke and his sister. On a routine visit to his GP, they notice a number of bruises on his face and abdomen.

Child protection procedures

In your country...

17. What procedures are in place to safeguard Luke in the primary health care setting? (Please provide details)

18. What procedures are in place when a child protection concern is identified by a health care professional in the primary health care setting? (Please provide details of the notification and referral process)

19. What procedures are in place to safeguard children, such as Luke, who may have cognitive or communication impairments? (Please provide details)

Alternative care arrangements

In your country...

20. What alternative care arrangements are available to Luke if his parents can no longer care for him? (Please tick all that apply)

- Foster care
- Informal care with friends or relatives
- Residential care
- Other, please specify:

Please provide details on the alternative care arrangement in your country.

21. Are there specialist alternative care arrangements for children with complex health care needs such traumatic brain injury (i.e. the care providers have training in caring for a child with complex health care needs)?

- Yes No

If yes, please provide details.

22. Would the type of alternative care arrangement differ if Luke had a severe intellectual impairment (e.g. unable to attend school, or complete daily tasks such as personal care)?

- Yes No

If yes, please provide details.

23. Would the type of alternative care arrangement differ if Luke had a severe physical impairment (e.g a spinal injury)?

- Yes No

If yes, please provide details.

24. Who is involved in decisions about Luke's health care once he is living in alternative care? (Please provide details)

Supporting information

Research, guidelines, or policy documents

Please provide links or references (including non- English documents) to any relevant policy documents, or research reports (non-scientific journals) on the topic of social care support for children with traumatic brain injury.

Any other comments

Please provide any further comments on the provision of social care support for children with complex health care needs/ traumatic brain injury in your country.

**Thank you for completing this questionnaire.
Please provide the names and contact details of all those who provided feedback, so that
we may acknowledge their contribution in our final report.**

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Appendix B: Supplementary Country Agent information

Table 8: Legal and policy frameworks for social care and child protection

	Child protection legislation	Central authority responsible for social care of children with complex needs	Social Care Legislation
	<i>Yes/ No/ Other</i>	<i>Yes/ No/ Other</i>	<i>Yes/ No/ Other</i>
Austria	Yes (Law for Child & Youth welfare) ^{ab}	No ^{ab}	Yes (Federal Laws on Social Welfare) ^{ab}
Croatia	Yes (Family Law) ^{ab}	Yes (govt. dept. - Ministry of Social Policy & Youth) ^a	Yes (Law on Social Care) ^{ab}
Cyprus	Yes (Children's Law) ^{ab}	Yes (govt. dept. - Department of Social Inclusion) ^{ab}	Other (Across a number of different legal instruments) ^{ab}
Czech Republic	Yes (Socio-Legal Child Protection) ^{ab}	No ^{ab}	Yes (Social Service Law)
Estonia	Yes (Child Protection Act) ^{ab}	Yes (agency - Estonian Social Insurance Board) ^{ab}	Yes (Social Welfare Act) ^{ab}
Finland	Yes (Child Welfare Act) ^{ab}	No ^{ab}	Yes (Social Welfare Act) ^{ab}
Germany	Yes - Federal Law on Child Protection	No ^{ab}	Other (Across a number of different legal instruments)
Greece	Yes (Law on Domestic Violence) ^{ab}	(Yes – agency – National centre for social solidarity (E.K.K.A)) ^{ab}	Yes (Development of the National System of Social Care and other provisions) ^{ab}
Hungary	Yes (Child Protection and Guardianship Act) ^{ab}	No ^{ab}	Yes (Act on social care and social administration) ^{ab}
Iceland	Yes (Child Protection Act) ^{ab}	No ^{ab}	Yes (Social Care Act) ^{ab}
Ireland	Yes (Children First Act) ^{ab}	Yes (agency - HSE) ^{ab}	Other (Across a number of different legal instruments) ^{ab}
Italy	Yes (Measures against violence in family units) ^{ab}	No ^{ab}	Yes (Law for the realization of the integrated system of interventions and social services) ^{ab}
Latvia	Yes (Rights on Child Protection) ^{ab}	No ^{ab}	Yes (Social services and Social Assistance Law) ^{ab}
Lithuania	Yes (Rights on Child Protection) ^{ab}	No ^{ab}	Yes (Social Services Law with special provisions for social care) ^{ab}
Malta	Yes (Children and Young Persons Care Orders Act CAP 285) ^{ab}	Yes (Agency - SAPPOR) ^{ab}	Yes (Social Security Act) ^{ab}
Netherlands	Yes (Child and Youth Act) ^{ab}	No ^{ab}	Other (Across a number of different legal instruments) ^{ab}
Norway	Yes (Child Welfare Act) ^{ab}	Yes (Agency - The Office for Children, Youth and Family Affairs (Bufetat)) ^{ab}	Yes (Social Welfare Act) ^{ab}

Poland	Yes (Act on domestic violence prevention)	No ^{ab}	Other (across a number of different legal instruments) ^{ab}
Portugal	Yes (Law on the protection of children and youth at risk)	Yes (Across a number of govt. departments - with regional offices) ^{ab}	Yes (Social Security System) ^{ab}
Romania	Yes (Law 272/2004 regarding the Protection and Promotion of Children's Rights) ^{ab}	No ^{ab}	Yes (Law of Social Assistance) ^{ab}
Slovakia	Yes (Act on social and legal protection of children and social curatorship) ^{ab}	Yes (govt. dept. - Ministry of Labour, Social Affairs and Family)	Yes (Act No. 448/2008 on social services)
Spain	Yes (Juridical Protection of Minors) ^{ab}	No ^{ab}	Yes (Social Security Act + regional legal instruments) ^{ab}
Sweden	Yes (Law on the Care of Young) ^{ab}	No ^{ab}	Yes (Social Services Law, 2001) ^{ab}
UK (England)	Yes (Children Act 1989 & 2004) ^{ab}	No ^{ab}	Health and Social Care Act 2012 ^{ab}

Table 9: Community social care support for children with complex care needs (scenario = child with a traumatic brain injury)

	Practical support for parents	Counselling for children	Counselling for families	Respite services	Support for peer relationships	Parenting courses
Austria	Yes via child and youth centres	Yes via primary care, social care and mental health services ^a	Yes via child and youth centres ^a	Yes via social services ^a	Yes via school services ^a	Yes via child and youth centres ^a
Croatia	*	*	*	*	*	*
Cyprus	Not available ^a	Yes via social services ^a	Yes via social services ^a	Not available ^a	Yes via mental health services ^a	Not available ^{ab}
Czech Republic	Yes via social services, primary care & NGOs ^{ab}	Yes via child mental health services ^{ab}	Yes via social services, NGOs (parents) & child mental health services (siblings) ^{ab}	Yes via social services ^{ab}	Yes via school services ^a	Yes via mental health services, school services & NGOs ^a
Estonia	Yes via rehab services & social services ^{ab}	Yes via social services & mental health services ^{ab}	Yes via social services & mental health service & support groups ^a	Yes via rehab services & social services (location dependent) ^{ab}	Yes via school services & social services ^a	Yes via school services, social services & mental health services
Finland	Yes via social services	Yes via social services and/or mental health (needs dependent) ^a	Yes via social services and/or mental health (needs dependent) ^a	Yes via social services	Yes via social services ^a	Yes via social services ^a
Germany	Yes, via social paediatric centres, mental health services & educational services	Yes, via social paediatric centres, mental health services & educational services	Yes, via NGOs	Yes, for children with more severe health conditions via paediatric nursing homes or rehabilitation centres. For other conditions (i.e. diabetes): summer camps via NGOs/welfare organisations ^a	Yes, via school mental health services	Yes, provided within the statutory health insurance system (patient education program for parents) and via social services/youth welfare (positive parenting courses) ^a

Greece	Yes via social services, mental health services & NGOs ^a	Yes via mental health services & school services ^a	Yes via family services, mental health services & school services ^a	Yes (summer camps) ^a	Yes via mental health services & school services ^a	Yes via family services ^a
Hungary	Yes via PC and social services	Yes via social services ^a	Yes via family services	Yes via social services ^a	Yes via school services and social services	Yes via NGOs
Iceland	Yes, via health services, social services and/or NGOs ^a	Yes, via health services, social services and/or NGOs ^a	Yes, via health services, social services and/or NGOs ^a	*	*	*
Ireland	Yes via health services, social services & NGOs ^a	Yes via child mental health services ^a	Yes via NGOs & private orgs ^a	Yes via NGOs (state funded) ^a	Yes via rehab services, child mental health services and school services ^a	Yes via NGOs, primary care, mental health services ^a
Italy	Yes, via health/ social care professionals in local health units ^{ab}	Yes, via municipality social services ^{ab}	Yes, via mental health/ rehab specialists in local health units & support groups ^{ab}	Yes, via the local health units ^a	Yes, via health/ social care professional in local health units	Yes, via health/ social care professional in local health units
Latvia	Yes via social care, primary care & school services ^a	Yes via primary care & mental health services ^a	Yes via social care services ^a	*	Not available ^a	Yes, sometimes via NGOs ^a
Lithuania	Yes, via NGOs/ advocacy	Yes, via NGOs/ advocacy	Yes, via NGOs/ advocacy	Not available ^a	Not available ^a	Yes, via NGOs/ advocacy
Malta	*	*	*	*	*	*
Netherlands	Yes via social worker in rehab centre, social care services of municipality (youth department), or NGO (advocacy groups) ^{ab}	Yes, via social care (municipality youth department) ^a	Yes via social worker in rehab, via mental health services or private practices or social care (sister) ^a	Yes, via NGOs and municipality social care services, public funding/grants (PCB) ^a	Yes, via social care and mental health services ^a	Yes, via social care and mental health services ^a
Norway	Yes via social services ^a	Yes via social services & school services ^a	Yes via social services & school services (sibling) ^a	Yes via social services ^a	Yes via social services ^a	Yes via social services ^a

Poland	Yes via primary care, social services & NGOs ^{ab}	Yes via rehab services & social services ^{ab}	Yes via rehab services & social services ^{ab}	Not available ^{ab}	Yes via social services (counselling) ^{ab}	Yes via social services (counselling) ^{ab}
Portugal	Yes ^a	Not available ^a	Not available ^a	Not available ^a	Not available ^a	Not available ^a
Romania	Yes via rehab/ local day centres ^a	Yes via social care services (specialist counselling services) ^a	Yes via social care services (specialist counselling services) ^a	Not available ^a	Yes via social care services (specialist counselling services) ^a	Yes via social care services (specialist counselling services) ^a
Slovakia	Yes via local social care/work services ^a	Yes via mental health services/ specialist ^a	Yes via NGOs (not available for siblings) ^a	Yes via house nursing care ^a	Not available	Sometimes via support groups ^a
Spain	Yes via social care and primary care ^a	Yes via social care & mental health services ^a	Yes via social care & mental health services ^a	Yes via social care ^a	Yes via social care & primary care ^a	Yes via social care & primary care ^a
Sweden	Yes via disability services ^{ab}	Yes via disability service & child mental health services ^{ab}	Yes via disability service & child mental health services ^{ab}	Yes via municipality social services ^{ab}	Rarely available ^a	Yes via disability services ^a
UK (England)	Yes via specialist children services (clinical commissioning groups). ^{ab}	Yes via health services & specialist children services (clinical commissioning groups).. ^{ab}	Yes via NGOs	Yes via health services & specialist children services (clinical commissioning groups).. ^{ab}	Yes via health services & specialist children services (clinical commissioning groups).. ^{ab}	Yes via NGOs

^a Country agent response ^b Supporting policy documentation ^c Supporting research literature ^d Other external information sources * Insufficient information provided

Appendix C: Adaptations of the AF

C1: Overview of the 'Getting it right for every child model' in Scotland

The Scottish adaptation of a child-centric framework is called *Getting it right for every child* (GIRFEC) (it is a rough equivalent of the UK Every Child Matters framework).

The model was tested and evaluated before key elements of its approach were brought into law in 2014 through the Children and Young People (Scotland) Act 2014. The principles behind the approach are that it is child-focused; based on an understanding of the wellbeing of the child; based on tackling needs early; and requires joined-up working. The GIRFEC framework works through three concepts; the MyWorld triangle, well-being indicators, and a resilience matrix. These are used in the following way:

The 8 Well-being indicators are used at several stages: to identify, record and share concerns; to make plans for a child and take appropriate action; to review those plans and record outcomes of action

The My world triangle is used to identify strengths and pressures on the child and family, and along with specialist assessments, gather information about children's needs

The Resilience Matrix is used to help organise and analyse information gathered

A single agency plan or multi-agency Child's Plan, which has a common format, is created using the Well-being indicators. The plan builds in a review and records outcomes achieved.

(Scottish Government, 2013;14)

The MyWorld triangle is based on the AF-triangle (having been adapted slightly by the Scottish government to what were considered more appropriate factors). When a social care, medical, or other professional uses the MyWorld triangle the following aspects of the world children inhabit are taken into consideration; their developmental needs, their parent's capacity to address those needs and the wider social and economic environment (see Table 8 and Figure 6). The eight well-being indicators similarly take an ecological approach to the development of the child in assessing the needs of children and their families, aiming to cover (Scottish Government, 2016); the well-being indicators are *Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, and Included* (known collectively as SHANARRI).

A universal aspect of the framework in Scotland is the provision of a 'Named Person' for every child in Scotland.³⁸ This provision is in place to provide support in the event that a child, young person or their parents need information or advice; the role is typically held by a health worker in the case of small children, and a promoted teacher in the case of school-going aged children (Scottish Government, 2013). Local authorities in Scotland provide practice guidance for use of the GIRFEC model in their area; for a child who requires an assessment under this framework, a child's plan is produced in which support from either a single universal service, or several agencies is recorded, thus taking into account the multiplicity of services and professionals involved. Should the child's needs be complex, but met by universal services, then a practitioner from a universal service will become the Lead Professional. In order to ensure that a Child's Plan is managed properly the Lead Professional should work with the child, their

³⁸ A controversial measure

parents, the Named Person, and the relevant services. When the GIRFEC framework is applied, the needs of the family of the child are also considered. (Scottish Government, 2013).

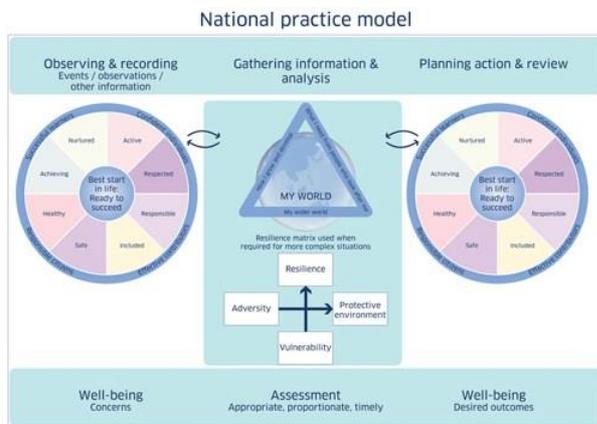


Figure 5: Diagrammatic representation of the *Getting it right for every child* framework showing three elements to assessment (resilience matrix displayed in centre)

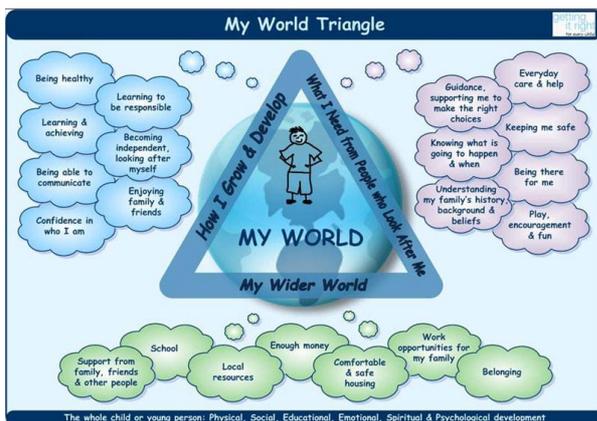


Figure 6: GIRFEC MyWorld triangle

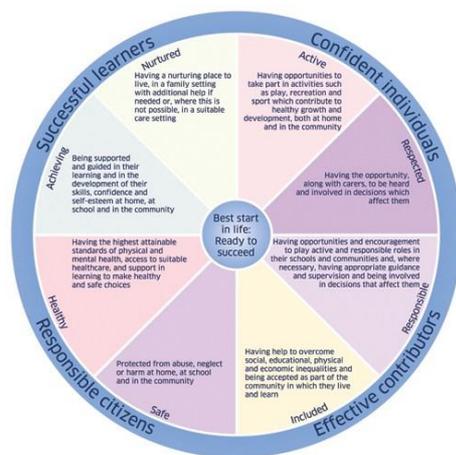


Figure 7: GIRFEC Eight well-being indicators

C2: Overview of the ‘Children’s needs in focus’ model in Sweden

The Swedish National Board of Health and Welfare (Socialstyrelsen) introduced the Barns behov i centrum (BBIC) (Children’s needs in focus) model, which is based on the AF model, in 2006 after a pilot phase. The BBIC model is used in Sweden for assessment, planning and follow up with children in need of support and/or protection from social services. It is used with children with complex care needs in these circumstances, however (as is the case in the UK) when assessing the health and social care needs which this population of children have due to their complex needs, a different framework will apply (under different legislation.) A model such as the BBIC was thought necessary in order to provide a more uniform approach to child protection as cases were being handled and documented differently throughout the country (BBIC final report, 2005). The model also serves to bring Swedish policy more in line with the UNCRC - the BBIC takes the UNCRC as its starting point, along with the Social Services Act, 2001; both place emphasis on children’s participation in decision-making (BBIC final report, 2005).

Swedish documentation on the BBIC acknowledges the influence of Ecological Systems Theory (see Bronfenbrenner, 1970) and Attachment Theory (see Bowlby, 1969); a BBIC triangle was created which follows the ecological approach of the AF triangle in denoting the importance of considering the child’s developmental needs, the capacity of their parents, and their family and the wider environment around them. The areas of consideration under each side of the triangle were originally the same as those of the original triangle, but when the BBIC model was revised in 2014 by the National Board of Health and Welfare the considerations of the triangle were reduced to four for each side of the triangle (see Table 8).

Table 10: Child’s needs captured on the BBIC triangle

The Child’s development	Health	Training	Feelings and Behaviour	Social relationships
Parental capacity	Basic Care	Stimulation and guidance	Emotional availability	Security
Family and Environmental Factors	Current Family Situation	Family background	Housing , Work and Economy	Social Networking and Integration

A detailed outline of how the BBIC works is presented in a 2014 Socialstyrelsen report (produced after the model had been revised). The first step is the completion of a preliminary assessment, for which the family and the child’s involvement is considered paramount; after this assessment social services make a decision on whether to initiate an investigation or not. The analysis and assessment of the child’s needs are based on the three principles of *risk*, *need* and *receptivity* (to intervention), and are completed by a social worker. An investigation can lead to one of several conclusions; no need for protection or support for either child or family; need for outpatient care in social services – with or without the child (if over 15), or guardian’s consent, or; need for placement in care– with or without the child (if over 15), or guardian’s consent. This approach includes provision to support the decision-making phase, and the on-going follow-up of cases (primarily through documentation, such as that to assist with measuring change and the organisation of follow-up meetings). It is facilitated through cooperation between health care and social service teams which work together to create a supportive network around the child (Socialstyrelsen, 2014).

The final report on the pilot stage of the BBIC in Sweden 'Child welfare in a state of change - Final report from the BBIC project' had a positive view of the model and encouraged its extension nationwide. It found that the model had contributed to strengthening the position of children; "children had become more active during the assessment and reviewing process because the social workers had been given greater awareness and knowledge of the children's needs" (BBIC, 2005;7)., as well as strengthening the involvement of parents. The report also found that the BBIC succeeded in providing a more structured, systematic way of working, and that it led to documentation which provided a basis for better and more balanced decision-making (BBIC, 2005).

Appendix D: Hardiker Model

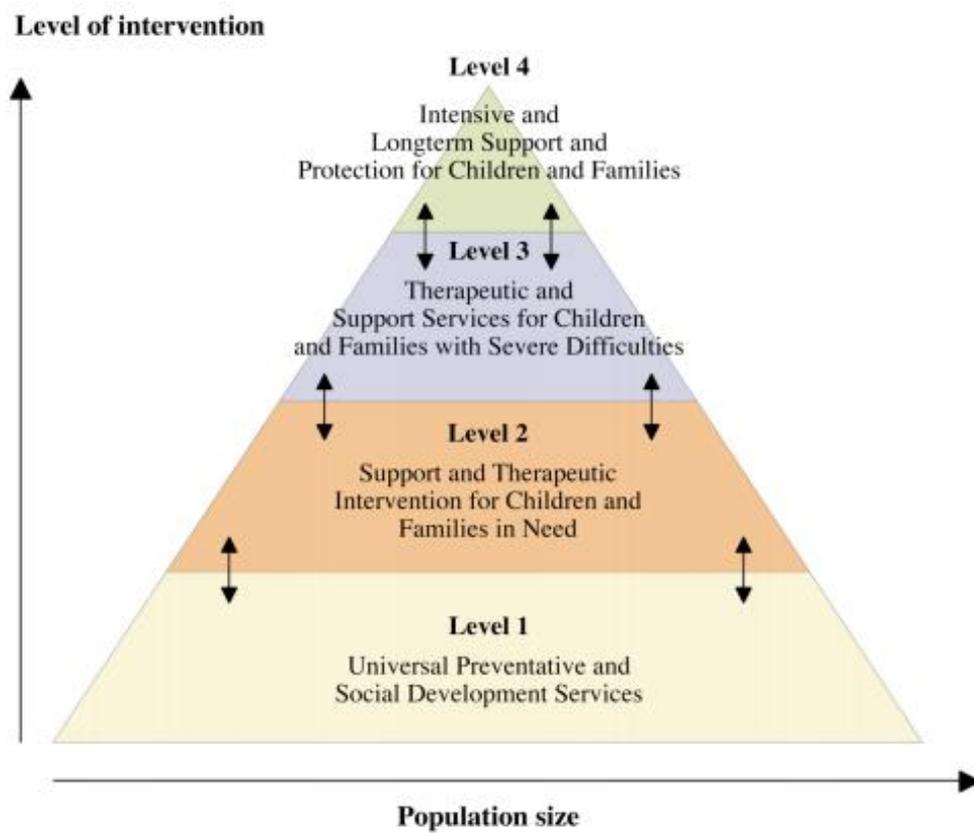


Figure 8: The Hardiker model (1991) (Owens, 2010).

