



Issues and Opportunities in Primary Health Care for Children in Europe

Services and Boundary Negotiations for Children with Complex Care Needs in Europe
Maria Brenner, Miriam O'Shea, Anne Clancy, Stine Lundstroem Kamionka, Philip Larkin, Sapfo Lignou, Daniela Luzi, Elena Montañana Olaso, Manna Alma, Fabrizio Pecoraro, Rose Satherley, Oscar Tamburis, Keishia Taylor, Austin Warters, Ingrid Wolfe, Jay Berry, Colman Noctor, Carol Hilliard,

Article information:

To cite this document: Maria Brenner, Miriam O'Shea, Anne Clancy, Stine Lundstroem Kamionka, Philip Larkin, Sapfo Lignou, Daniela Luzi, Elena Montañana Olaso, Manna Alma, Fabrizio Pecoraro, Rose Satherley, Oscar Tamburis, Keishia Taylor, Austin Warters, Ingrid Wolfe, Jay Berry, Colman Noctor, Carol Hilliard, "Services and Boundary Negotiations for Children with Complex Care Needs in Europe" *In Issues and Opportunities in Primary Health Care for Children in Europe*. Published online: 18 Apr 2019; 199-218.

Permanent link to this document:

<https://doi.org/10.1108/978-1-78973-351-820191014>

Downloaded on: 24 April 2019, At: 09:50 (PT)

References: this document contains references to 0 other documents.

The fulltext of this document has been downloaded 8 times since 2019*

Access to this document was granted through an Emerald subscription provided by All users group

For Authors

If you would like to write for this, or any other Emerald publication, then please use our Emerald for Authors service information about how to choose which publication to write for and submission guidelines are available for all. Please visit www.emeraldinsight.com/authors for more information.

About Emerald www.emeraldinsight.com

Emerald is a global publisher linking research and practice to the benefit of society. The company manages a portfolio of more than 290 journals and over 2,350 books and book series volumes, as well as providing an extensive range of online products and additional customer resources and services.

Emerald is both COUNTER 4 and TRANSFER compliant. The organization is a partner of the Committee on Publication Ethics (COPE) and also works with Portico and the LOCKSS initiative for digital archive preservation.

*Related content and download information correct at time of download.

Chapter 10

Services and Boundary Negotiations for Children with Complex Care Needs in Europe

Maria Brenner, Miriam O'Shea, Anne Clancy, Stine Lundstroem Kamionka, Philip Larkin, Sapfo Lignou, Daniela Luzi, Elena Montañana Olaso, Manna Alma, Fabrizio Pecoraro, Rose Satherley, Oscar Tamburis, Keishia Taylor, Austin Warters, Ingrid Wolfe, Jay Berry, Colman Noctor and Carol Hilliard

Abstract

Improvements in neonatal and paediatric care mean that many children with complex care needs (CCNs) now survive into adulthood. This cohort of children places great challenges on health and social care delivery in the community: they require dynamic and responsive health and social care over a long period of time; they require organisational and delivery coordination functions; and health issues such as minor illnesses, normally presented to primary care, must be addressed in the context of the complex health issues. Their clinical presentation may challenge local care management. The project explored the interface between primary care and specialised health services and found that it is not easily navigated by children with CCNs and their families across the European Union and the European Economic Area countries. We described the referral-discharge interface, the management of a child with CCNs at the acute–community interface, social care, nursing preparedness for practice and the experiences of the child and family in all Models of Child Health Appraised countries. We investigated data integration and the presence of validated standards of care, including governance and co-creation of care. A separate enquiry was conducted into how care is accessed for children with enduring mental



© European Commission. Published by Emerald Publishing Limited. This chapter is published under the Creative Commons Attribution (CC BY 4.0) licence. Anyone may reproduce, distribute, translate and create derivative works of this chapter (for both commercial and non-commercial purposes), subject to full attribution to the original publication and authors. The full terms of this licence may be seen at <http://creativecommons.org/licences/by/4.0/legalcode>

health disorders. This included the level of parental involvement and the presence of multidisciplinary teams in their care. For all children with CCNs, we found wide variation in access to, and governance of, care. Effective communication between the child, family and health services remains challenging, often with fragmentation of care delivery across the health and social care sector and limited service availability.

Keywords: Acute-community interface; access to care; complex care needs; complex mental health care needs; integrated care; child

Introduction

Every child has a right to the highest attainable standard of health care, including those with complex care needs (CCNs) (see Chapters 4 and 16), which is a cohort of children often neglected in policy and research priorities in primary care. Improvements in neonatal and paediatric care mean that more children with CCNs are surviving into adulthood, but by their very nature, children with CCNs, and their families, place great challenges on healthcare delivery in the community. Although the provision of care closer to home for such children is a policy objective internationally, in most countries, the necessary integration of health services is insufficient, and there is wide variation in systems of care for these children. As a result, the interface between primary care and more specialised services is not easily navigated by children and families across the European Union (EU) and European Economic Area (EEA) countries. To identify the particular challenges faced by children with CCNs and their families, we explored the referral-discharge interface, the management of the child with CCNs at the acute–community interface, the social care interface, nursing preparedness for practice and the experiences of the child and family (Brenner, O’Shea, & Larkin, 2017; Clancy, Montañana-Olaso, & Larkin, 2017; Keilthy, Warters, Brenner, & McHugh, 2017; Wolfe, Lignou, & Satherley, 2017) by means of an extensive set of questionnaires to the MOCHA country agents (CAs) (see Chapters 1 and 2).

Data Integration

Collectively, we focused on two key areas in the integration of data to identify the issues that emerged pertaining to the optimum care for children with CCNs at the acute–community interface: to demonstrate how each area was linked and to identify how there would be meaningful integration of the various data gathered. We used business process analysis to reconstruct the child’s care pathway through the identification of the actors and the activities performed to address a child’s CCNs. This often complex care process was described in the project by using Unified Modelling Language (UML) methodology (Luzi, Pecoraro, & Tamburis, 2016). In addition to this, the experiences of children

and young people living with long-term conditions were sought by MOCHA project partners, DIPEX International (see Chapter 3). This group of qualitative interviewers conducted interviews with young people and their parents to provide insight into the experiences of children and parents in terms of primary health care for children and the primary/secondary care interface. It was not possible nor methodologically appropriate to conduct these interviews in all MOCHA countries, so qualitative researchers from five representative countries worked collaboratively to explore patients' experiences in Czech Republic, Germany, The Netherlands, Spain and United Kingdom.

We identified key themes from each area of work and the core facilitators of optimum integration of care at the acute–community interface. Due to the complexity of this subject, we verified the findings of our integration of the data to ensure the findings were supported by exemplars of good practice, provided through self-report of the CAs in the participating countries. This occurred in two ways, the CAs read through our draft reports and commented on the representation of their data and the research team returned to the raw data to verify each standard which emerged in our collective analysis (see also Chapters 1 and 2).

Validated Principles and Standards of Care for Children Living with Complex Care Needs

We grouped our data into three principles and standards of care: access to care, co-creation of care and effective integrated governance. For each of these principles and standards, CAs in 30 countries were asked questions about the experiences of children with three tracer conditions needing complex care input. These three tracer conditions were chosen and presented to the CAs by means of a short vignette. This process allowed the exploration of a child's experience and the wider family experience of caring for a child with considerable needs. The tracer conditions also allowed us to cover a wide variety of ages from infant to 18 years of age (for a full explanation and analysis, see [Brenner et al., 2017](#), [Brenner et al., 2018a, b](#)). The three tracer conditions were as follows:

- (1) traumatic brain injury (TBI) (15-year-old boy, previously healthy who suffered a head injury in a skateboard accident) – responses from 26 out of 30 MOCHA countries;
- (2) long-term ventilation (LTV) (18-month-old boy, with chronic lung disease due to bronchopulmonary dysplasia; and ventilator dependent since birth) – responses from 27 out of 30 MOCHA countries; and
- (3) intractable epilepsy (seven-year-old girl with intractable epilepsy, suffering from multiple seizures daily, she comes from a non-EU migrant family, her father only speaks his native language, and her mother has basic knowledge of the official language of their host country) – responses from 27 out of 30 MOCHA countries.

Access to Care

We explored the access to care experienced by a child with CCNs, in terms of appropriateness of care, as well as availability of services and geographical, linguistic and cultural access to care. Our findings for the three tracer conditions, including the key issues are described in [Table 10.1](#).

Co-creation of Care

This principle encompasses a number of key features of managing the health and care of a child with complex needs, including coordinating the services required, engagement and empowerment of the family (and child if able) to manage care at home where possible, support and advocacy where needed and an overall plan for long-term care. Our main findings are shown in [Table 10.2](#), and more detailed results and analysis can be found in [Brenner et al. \(2017a, b\)](#), [Brenner et al. \(2018a, b\)](#).

Effective Integrated Governance

This is an aspect of care that ensures good quality of care and also encompasses the mechanisms by which a family can access and obtain help to co-ordinate the care they need in the community. This is a principle that many EU and EEA countries struggle to uphold, and concerns were raised about inequity of service provision (see also Chapter 5). Examples of our findings are shown in [Table 10.3](#). For more detailed analysis and data, see [Brenner et al. \(2017a, b\)](#), [Brenner et al. \(2018a, b\)](#).

Services and Boundary Negotiations for Children with Complex Mental Health Needs in Europe

Children with complex mental care needs are defined as those with substantial care needs resulting from one or more conditions, which require access to multiple health and social support services. These needs can be best fulfilled when their care is integrated so that children and their families receive a continuum of preventive and curative services according to their needs over time and across different levels of the health system. Thus, in addition to describing the approach to managing the care of children with enduring complex mental health care needs, the aim of this study was also to identify facilitators and barriers to achieving a continuum of care at the interface of primary care ([Brenner et al., 2017a](#); [Kamionka & Taylor, 2017](#)).

Methods

In addition to an extensive survey of the MOCHA CAs, this study incorporates a qualitative exploration of patient and family experiences (through DIPEX International, see Chapter 3), business process models of actors involved in

Table 10.1. Access to care for children with complex care needs.

Principles and Standards of Care	Supporting Data of Optimum Practice Identified from MOCHA and Identified Deficits
Principle 1: Access to care	
1.1 Children have access to age-specific and developmentally appropriate care	Data from Portugal highlights the benefits from an adolescent perspective: <i>When this is the case, care is much more adjusted and adolescents get much more integrated care across several areas: developmentallypuberty; mental health, oral health, vision health, hearing assessment, sexual health nutrition and counselling.</i> (Portugal)
1.2 There is a pathway in place to access non-urgent specialist care in the community 24/7	Several countries provided examples of good practice regarding access to urgent care in the community, including having 24/7 access to a physician to seek clinical care advice
1.3 Where possible children are cared for by the same doctor and nurse on each consultation	Several countries identified a need for a comprehensive system of care for children with disabilities, which can provide consistent care to children and their families
1.4 Community complex care centres are established where the population and specialist expertise exists to support the child with CCNs and their family	<i>Centres for complex care [...] to support of the families of children with disabilities and chronic diseases [...] treatment and medical and psychosocial rehabilitation; long-term treatment and rehabilitation [...] education of parents for home-care [...].</i> (Bulgaria)
1.5 There is technical support in the community to assist parents caring for a child living with CCNs in the home	<i>The parents together with the transitional care person of the hospital and the social worker discuss and organise all the technical equipment, social support which is needed.</i> (Austria)

Table 10.1. (Continued)

Principles and Standards of Care	Supporting Data of Optimum Practice Identified from MOCHA and Identified Deficits
1.6 Electronic health records are used to support communication and continuity of care across the acute–community interface	<i>All health care providers should use digital records [...] where the next care providers and parents can get an overview of services performed in the past as well as a plan for the future.</i> (Estonia)
1.7 Children and families have access to community pharmacists	<i>A community-based pharmacy system exists whereby the pharmacist is part of the primary care team, aware of the child's background and illness.</i> (Estonia and Portugal)
1.8 A child living with CCNs receives ongoing preventative care screening and developmental checks	61.4% of countries responding have mechanisms in place to support the preventative screening, assessment and referral of children living with CCNs
1.9 The results of all screening are disseminated to all health services caring for the child and communicated to the child's parent(s)/guardian(s)	Half of all countries responding have mechanisms in place to disseminate the results of health screening to providers engaged in the care of children with intractable epilepsy Half of all countries responding have mechanisms in place to disseminate the results of all screening to the parent(s)/guardian(s) of children with intractable epilepsy
1.10 Families have access to a transportation service that can enable the child, and their assisted technology devices, to attend daily activities and health and social care visits	Parent(s)/guardian(s) receive assistance from the State and healthcare providers with the daily transport requirements of their children in approximately a quarter of all countries responding
1.11 All information provided to families of children living with CCNs is linguistically appropriate	Over one-third of all countries responding have mechanisms in place to support the provision of linguistically appropriate information material to the families of children living with CCNs

1.12 All information provided to families of children living with CCNs is culturally appropriate

1.13 When a child living with CCNs has a medical crisis there is direct access to, and discharge from, a Paediatric ED and/or a Paediatric Intensive Care Unit

1.14 Children have timely assessment for, and access to, rehabilitation services

1.15 Paediatric palliative care services are available to the child and family when required.

1.16 Children have timely access to respite care services

1.17 Children have access to diagnostic tests in primary care that enable prevention and early detection of health concerns

Over one-third of all countries responding have mechanisms in place to support the provision of culturally appropriate information material to the families of children assisted with LTV or with intractable epilepsy

Nearly two-thirds of all countries responding have a process in place which facilitates direct access to/from a Paediatric Intensive Care Unit for children assisted with LTV

An excerpt from data highlights some challenges in relation to the provision of rehabilitation services for adolescents following a TBI:

[...] accessibility varies a lot. In several local rehabilitation centres, the staff have very little knowledge about the need for intensive training after a TBI. (Sweden)

Nearly two-thirds of countries responding have paediatric palliative care services available when required for children assisted with LTV

The absence of respite care services for children living with CCNs was repeatedly documented as a major concern

More than half of countries responding have mechanisms which support and facilitate preventative screening and developmental assessments for children with intractable epilepsy

Table 10.2. Co-creation of care for children with complex care needs.

Principles and Standards of Care	Supporting Data of Optimum Practice Identified from MOCHA and Identified Deficits
Principle 2: Co-creation of care	
<p>2.1 A discharge planning coordinator is available to the child and family when transitioning from the acute to the community setting</p>	<p>Nearly two-thirds of countries responding have a discharge planning coordinator in place for the transition of an adolescent with a TBI from the acute hospital environment to the community-based setting</p>
<p>2.2 There is a standardised system to identify the clinical support needs for the child transitioning to home</p>	<p><i>Parents will be trained in the ICU in tracheostomy care, equipment, medicines etc. by the physicians and nurses in charge prior to their discharge to home. (Austria)</i></p>
<p>2.3 Parents are supported to be clinically ready to care for their child at home, in an incremental manner</p>	<p><i>[...] the child comes to a step down unit, where the parents share a greater part of care themselves, but know they can always call someone for support [...] Only when the parents feel safe and do well, and agree, the child will be discharged to home. (Austria)</i></p>
<p>2.4 There is a written personalised plan of care for the child, developed in consultation with the child’s parent(s)/ guardian(s) and members of the healthcare team</p>	<p>The majority of countries responding develop a written personalised care plan for a child assisted with LTV in consultation with members of the health care teams</p>
<p>2.5 A named care coordinator is appointed to the child living with CCNs and their family to support multidisciplinary engagement and care in the community</p>	<p>A number of countries provided good examples highlighting the importance of the care coordinator role in supporting integration at the acute–community interface</p>
<p>2.6 Family advocacy groups are involved in making recommendations to home and community-based services</p>	<p>Over one-third of all countries responding have input from a family advocacy groups for children following a TBI or children assisted with LTV</p>

2.7 There is a standardised assessment of sibling support needs

2.8 The child, their parent(s)/guardians(s) and siblings have access to psychological support

2.9 Children are included in national quality improvement initiatives for their care

2.10 Data are collected on the child's experience of care

2.11 Data are collected on the experience of care from the perspectives of parents(s), guardians(s) and siblings

2.12 A plan of care is prepared with adult healthcare services before an adolescent is transferred from paediatric services

2.13 Data are collected on the experience of transitioning from paediatric to adult services from the perspective of the adolescent

2.14 Data are collected on the experience of transitioning from paediatric to adult services from the perspective of the parent(s)/guardians(s)

For siblings of children and/or adolescents with TBI there are 'Siblings-days' [...] they get information about TBI and they can share their experiences. (Netherlands)

The majority of countries responding indicated access to psychological support for families from professionals with paediatric expertise

Over one-third of all countries responding include the views of children in national quality improvement initiatives

Only one-sixth of all countries responding collect data from adolescents with TBI (where cognition allows)

Over one-third of all countries responding collect data on experience of care from the perspective of parent(s)/guardian(s) of children living with CCNs

One-third of all responding countries have a plan of care prepared with the adult healthcare service providers prior to the transfer to adult services

No country reported that they collect data on the transition of care of adolescents with a TBI

One country reported that they collect data on the experience of transitioning from paediatric to adult services from the perspective of parent(s)/guardian(s) of adolescents with a TBI

Table 10.3. Effective integrated governance for children with complex care needs.

Principle 3: Effective Integrated Governance	
3.1 Primary care providers have access to specialist support when caring for a child living with CCNs	The majority of responding countries indicated that primary care providers routinely have access to specialist support when caring for a child living with CCNs
3.2 Specialist advanced nurse practice roles are developed in the community for the care of children living with CCNs	<i>Recent developments have included the development of Advance Nurse Practitioner posts in Children's Epilepsy which respondents unanimously agreed was a significant positive move to enhance access to services.</i> (Ireland)
3.3 There are standardised systems in place for the assessment of the child living with CCNs in the community, including the deteriorating child	This was repeatedly identified as an issue of potential inequity in access to, and delivery of, care to these children and their families
3.4 There are standardised processes for the clinical handover of the child living with CCNs to and from acute care services	Very few countries indicated any evidence of a strategic and systemic network to co-ordinate care. Where reported, this seemed dependent on personal and professional relationships
3.5 There is systematic identification of all health and social care providers who care for a child living with CCNs	Over one-third of all countries responding have a system in place that can identify all of the healthcare providers caring for children living with CCNs
3.6 There is systematic identification of all voluntary agencies who care for children living with CCNs	The role of the voluntary sector in providing primary care services was widely viewed as an increasing ad hoc network, requiring governance to ensure quality of care delivery
3.7 There is a system in place to govern all care delivery to the child living with CCNs in the home	The majority of countries responding reported challenges in governance of care in the home and suggested that a national strategy on the management of children on LTV would begin to address many of the issues raised

3.8 There is specialist training in the care of children with CCNs for primary care providers caring for these children and their families

3.9 There is appropriate education for all social care staff caring for children living with CCNs

3.10 There is a retention policy for skilled healthcare staff who care for children living with CCNs

3.11 There is a national data base of children living with CCNs

3.12 Quality assurance mechanisms are in place for service providers caring for children living with CCNs

3.13 There are cross-border initiatives in place where no specialist centre exists nationally for children living with CCNs

3.14 There are national integrated care programmes in place to support care delivery at the acute–community interface

3.15 There is a school health system to support the child living with CCNs

Inadequate education of nursing staff to provide care was repeatedly reported as a significant challenge to the provision of optimum care

Inadequate training of social care staff was repeatedly reported as a significant challenge to the provision of optimum care

Training and retention of skilled healthcare staff was identified as a key facilitator for the integration of care across all exemplar complex conditions

National databases of children living with CCNs were repeatedly identified as necessary to support optimum integration of care for children living with CCNs

Over one-third of all countries responding indicated that they have mechanisms in place to support quality assurance

Given the variance in the specialist care, the needs of children living with CCNs across the EU/EEA cross-border specialist healthcare initiatives were identified as a critical part of the healthcare infrastructure to support access to care, particularly for island nations

The establishment of integrated care programmes was one of the most significant changes to occur during the last five years in relation to integration of care for all exemplar complex conditions

The absence of a structured school health system was identified as a barrier to equitable access to education for children living with CCNs across the EU/EEA

Table 10.3. (Continued)

Principle 3: Effective Integrated Governance	
3.16 There is appropriate training for school teachers and education support staff when a child is living with CCNs	The introduction of specialised training for school teachers was identified as a significant and positive trend across the EU/EEA
3.17 There is special reference to promoting the welfare of children with disabilities within wider child protection legislation	In some countries, the welfare of children with disabilities is promoted within the wider child protection legislation; other countries aspire to this to support the care of children living with CCNs
3.18 There is safeguarding training for children with communication difficulties for all health and social care staff	Training for professionals to communicate with individuals with disabilities that impact on their communication, as well as online peer-support for professionals, is available in a small number of countries

complex care (using UML) and a mixed-methods study conducted by Murdoch Children's Research Institute in Australia, which was conducted in collaboration with the MOCHA project. The range of methods and perspectives used adds to the understanding of the complex and multi-faceted topic of care for complex mental health conditions.

Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) were selected as tracer mental health conditions, as they are characterised by their persistent care needs across the specialised and general psychiatric, medical and social services (Lai, Lombardo, & Baron-Cohen, 2013; Thapar & Cooper, 2015). The main part of our investigation consisted of a mixed-methods study of 30 European countries to collect survey data and qualitative commentary from key informants in each country (see Chapter 1). The questionnaire was composed of patient vignettes and the adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs and Complex Care European Survey of Change (Association of Maternal and Child Health Programs and Lucile Packard Foundation for Children's Health, 2014). The analysis of the qualitative responses from the MOCHA CAs was conducted to identify basic, organising and global themes that influence the interface of primary care. The methodology adopted in studying the management of children and adolescents with complex mental healthcare conditions is described in full in Kamionka and Taylor (2017).

Key Themes Influencing Care for Children with Enduring Mental Health Needs at the Primary Care Interface

The results from this study fall into two main domains: firstly, relating to coordination within multidisciplinary structures, and secondly, relating to attitudes and awareness within the wider societal context. The public and political context provides the framework within which organisations, practitioners and parents must operate when providing and supporting services, communicating with each other and advocating for a child's care (see also Chapters 16 and 17). Access to appropriate care, parental involvement and multidisciplinary expertise were identified as the key interrelated factors facilitating and being facilitated by coordination. This is illustrated in Figure 10.1.

We developed a business process model (UML) to illustrate some of the key processes and complexity involved in the care of children with ADHD and ASD, highlighting the actors and level of collaboration involved both in providing health and social care preventive screening and developmental checks, and in the development and implementation of a written personalised plan. Our analysis suggests that collaboration is more developed for the care of children on the autistic spectrum than for children with ADHD and for health care more than for social care. This is illustrated in Figure 10.2.

Key principles in providing care for children with complex mental health needs from multiple perspectives were derived under three main principles; access to care, parental involvement and multidisciplinary.

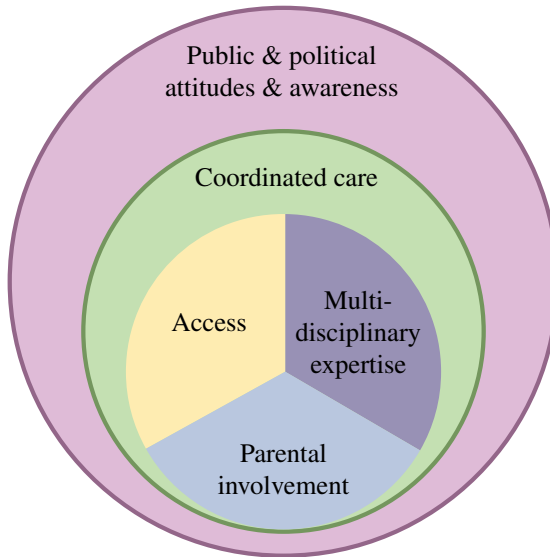


Figure 10.1. Model of key themes influencing the care of children with enduring mental health needs at the primary care interface.

Access to Care

Children with complex mental healthcare issues are in need of multi-faceted care services, and this premise was acknowledged across all of the EU/EEA countries. Thus, the term access to care covers the area of availability of specialist at a knowledge-based and a structural level. Access to care includes equity of access to normal primary care and other services for children with an identified mental health condition. This proved to be a strong theme as services for both ADHD and ASD suffered from a shortage of specialist care at different points during the care continuum.

- *Ongoing screening and developmental checks should be provided regardless of detected mental health conditions.* Several countries responded that these children are not necessarily being offered ongoing screening and developmental checks. Many reported that elements regarding developmental health were incorporated into the personalised written plan of care but there was no consensus on which elements of development health should be included.
- *Care provision should be accessible regardless of the geographic location of the child and family.* The vast majority of the countries described geographic differences where clustering of services and expertise in some regions leave other regions with less coverage.
- *Care services to supporting children with mental health conditions should be in place in primary, secondary and social care.* Across the EU/EEA countries, it was widely recognised that the care services should exist across all the care

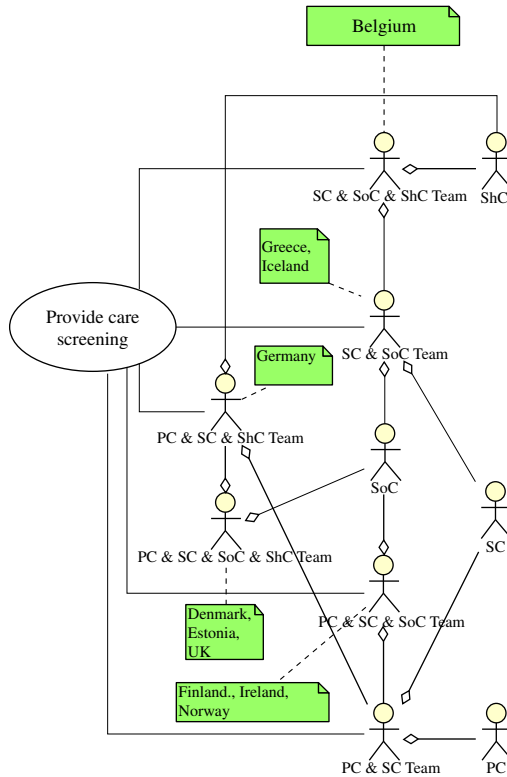


Figure 10.2. An Example of UML use of case diagram: provision of screening services for children with autism. *Notes:* PC = primary care professionals; SC = secondary care; SoC = social care; ShC = school care.

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

- *Access to care should follow a stepped care approach.* Most countries reported following a stepped care approach in providing care which places primary care in a central role.
- *Consideration should be given to the regional differences of young people and their families.* A range of feedback highlighted the need to incorporate the differences in culture and structure of families and local communities. [...] *Family centred services should be an important part of the organisation and development of all services. However, as yet there is limited formal implementation of family centred services in the country (Iceland, ASD).*
- *Care pathways should be put in place to support care delivery at the interface between services.* Most countries noted the difficulties in providing care across sectors. Three countries reported to have specific care pathways for children

with either ADHD or ASD. The rest had only partially developed pathways or no pathways at all. Of those who care pathways, few had clearly described roles for the different care providers.

- *There should be a review of fee-based care, which can act as a barrier to accessing care for low-income families.* Several countries reported to have fee-based care systems, especially in secondary and tertiary care. This was not noted in the Scandinavian countries.
- *Transparent referral procedures support continuity of care.* This is necessary to support safe care given the number of people involved in care provision.
- *Attention to transition between services and/or lifespan changes are a part of the personal care plan of every child with mental health conditions.* The vast majority reported not to have policies or procedures to ensure continuity of care when transitioning to adult services. Many countries identified lack of knowledge about the persistent nature of ADHD as a barrier to continuity of care in this transition period.
- *Political awareness and collaboration is necessary to facilitate access to different services.* Nearly all of the EU/EEA countries reported that there is a long-standing problem of disinterest and a lack of political awareness of ASD and ADHD which was identified as a barrier in ensuring care services. Nonetheless several countries state that public and political awareness has increased within the last five years.

Parental Involvement

As part of co-creation of care, it is important that parents, and where possible, the child, are involved in any care plan and supported to carry out that plan in a practical manner. We asked about particular means by which this can be achieved.

- *Parents should be included as partners in their child's care.* Parental involvement was consistently identified as key to insuring, facilitating and coordinating care.
- *Parents should receive information about their child's care in a linguistically and culturally appropriate manner.* It was widely agreed across EU/EEA countries that this linguistic or culturally appropriate information was not prioritised. However, parents/guardians of children with ASD were in general more involved in reviewing materials than parents/guardians of children with ADHD.
- *The families of children with mental health conditions should be provided with psychosocial support.* There was consensus about the need for parents and sibling of children with ASD and ADHD to receive psychosocial support.
- *Parents and parent advocacy groups should be invited to participate in the development of policies and procedures affecting their child.* The specialist knowledge of parent and parent advocacy groups about the children's care needs was broadly recognised between the countries as facilitator in ensuring better care services and increase awareness.

- *Parents should be provided with an overview of the skill set of the caregiver caring for their child, and of their specific professional role.* An overview of caregivers was identified as supporting the care plan.
- *Parents should be provided with an overview of all possible accessible care services.* Parents/guardians were identified as the main help seeker and care facilitator.
- *Parents should have a voice in quality assurance at regional and national level.* Parents were identified as crucial in assessing quality. It was found that parents, and parent advocacy groups, of children with ASD positively influenced a focus on quality assurance.

Multidisciplinary Teams

The care provided to children with ASD or ADHD involves many different healthcare and social care professionals located in several different settings. This study identified considerable evidence that good communication between multidisciplinary teams improves outcomes for the child and facilitates better working conditions for the service providers. In the context of CCNs for those with long-term mental health conditions, we identified a number of key facilitating factors.

- *There needs to be a level of knowledge regarding childhood mental health conditions which should be insured, both with regard to the health and social care aspects of treatment.* The basis for multidisciplinary teams' collaboration was a commonly shared knowledge and there was a clear tendency among the EU/EEA countries that the level of knowledge was lacking, particular in social services. Gaps in knowledge of mental health conditions was identified across the EU/EEA for health and social care professionals.
- *Responsibilities between caregivers should be clearly communicated and coordinated.* Many countries stated difficulties in insuring continuity of care across sectors because of a lack of or undefined cross-sectoral communication and coordination.
- *A personalised care plan should be accessible for all professionals who are involved in the child's care, across both sectors and services.* Due to the multifaceted care needs, every country in the study had identified several care providers. The written care plan was the main shared document which could facilitate communication and coordination between professionals.
- *The results of screening and assessments should be accessible for all caregivers.* Many countries reported that their healthcare professionals corresponded on assessments, however few countries reported that reports were shared with social care services.
- *Professionals across sectors should be included as partners in regional and national quality assurance initiatives.* In general, the healthcare sector was more influential at national level than social care.
- *A standard for the multidisciplinary approach in care provision for children with mental health conditions should be encouraged as it would heighten the degree of coordination between healthcare and social care services.* Despite the different structures across the EU/EEA countries, all aimed at incorporating a

multidisciplinary approach in the care provision. (The different organisations can be seen in the UML diagram.)

- *Primary care providers should have specialised training in the care and treatment of children with mental health conditions.* Nearly every country had primary care – mainly the GPs – as gatekeepers to care. *Mostly family physicians/GPs or primary care paediatricians [are responsible for providing general health care to these children] (but most of them have very little knowledge about the treatment of such kids), Lithuania, ADHD.*
- *Social care providers should also have specialised training in the care and treatment of children with mental health conditions.* Many countries identified a gap in specialist knowledge in social care.
- *All personnel involved in the treatment of children with mental health conditions should have training in the coordination of care packages.*
- *School health systems should provide specialised training and need to be able to support and educate the child with a mental health condition.* Many countries identified schools as a central scene for both identification of the child's mental health needs and the place for providing community-based care. Many countries identified specialised trained professionals in schools as a scarce yet highly important resource.

Summary

Children with CCNs and their families place great challenges on health and social care delivery for many reasons: they require dynamic and responsive health and social care over a long period of time; they require organisational and delivery coordination functions; health issues such as minor illnesses, which are normally presented to primary care and must be addressed in the context of the complex health issues; and finally. Our collective findings in MOCHA are that the existing integration of health and social care services is generally found to be insufficient, with wide variation in access to, and governance of, care for these children. It is acknowledged that some initiatives are beginning in this area across the EU; however, there remain extensive challenges. These include communication of a child and family's needs at the acute–community interface, confusion over points of accessing care and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multidisciplinary team when families cross between acute and community care services. There is a small window of opportunity in a child's life to address key issues of care that can have a positive or negative influence on subsequent adaptation and coping by a child living with CCNs and their family. This need for timeliness in care transcends the principles and standards developed, cognisant of the initial need for a timely transition to home when a child has CCNs, the ongoing importance of timely assessment of needs, the timely identification of any deterioration and the timely management of care to support transitions to end-of-life care.

Similarly, children with complex mental health conditions face challenges due to the fragmentation of the continuum of care delivery across primary /

secondary care and across the health and social care sector. In most European countries, the structure of care is moving towards more specialisation in both the health and social care systems, which have increased needs for a comprehensive coordination of services and a higher demand for specialists in mental health care. In addition, the gaps in the continuum of care also stem from the limited availability of services for children and young people with mental health problems. Thus, the barriers to care delivery are not only rooted in clinical complexities, but also rooted in complexity at the meso-level of service design. A general lack of public and political awareness of mental health disorders can hinder the development of optimal cross-sectoral care pathways. Fundamental to the discussion regarding optimal care integration for children with complex mental health needs are issues specific to the exemplar conditions, as described, but further, these are also indicative of issues relating to mental health in general, in contrast with physical health. The care of children with mental health conditions depends on the discipline and perspective of clinicians, who are reliant on less demonstrable, externally measurable symptoms, resulting in a wider variety of possible treatment pathways. Care pathways in mental health are therefore very different from in physical health, where tangible symptoms can be measured. The multiple subjective perspectives as to the causal factors of childhood mental health problems and the subsequent impact of these perspectives in the preferred treatment options make uniformity in mental health service coordination problematic. However, the core principles of involvement of families in treatment, coherent transitions, multi-agency working and specialist training for professionals involved in the care of children will all benefit the improvement of care coordination and ultimately benefit the experience of children and their families.

References

- Association of Maternal and Child Health Programs and Lucile Packard Foundation for Children's Health. (2014). *Standards for systems of care for children and youth with special health care needs*. Washington: Association of Maternal and Child Health Programs. Washington. Retrieved from <https://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs>
- Brenner, M., Alma, M., Clancy, A., Larkin, P., Lignou, S., Luzi, D., ... Blair, M. (2017a). *Report on needs and future visions for care of children with complex conditions*. Retrieved from http://www.childhealthservicemodels.eu/wpcontent/uploads/20171130_Deliverable-D11-2.4-Report-on-needs-andfuture-visions-for-care-of-children-with-complex-conditions.pdf
- Brenner, M., O'Shea, M., & Larkin, P. (2017b). *Final report on the current approach to managing the care of children with complex care needs*. Brussels: EU Commission. Retrieved from <http://www.childhealthservicemodels.eu/publications/deliverables/>. Accessed on September 5, 2018.
- Brenner, M., O'Shea, M. P., Larkin, P., Luzi, D., Pecoraro, F., Tamburis, O., ... Blair, M. (2018a). Management and integration of care for children living with complex care needs at the acute–community interface in Europe. *Lancet Child and Adolescent Health*, 2(E11), 822–831. doi:10.1016/S2352-4642(18)30272-4

- Brenner, M., O'Shea, M. P., McHugh, R., Clancy, A., Larkin, P., Luzi, D., ... Blair, M. (2018b). Principles for provision of integrated complex care for children across the acute–community interface in Europe. *Lancet Child and Adolescent Health*, 2(11), 832–838. doi:10.1016/S2352-4642(18)30270-0
- Clancy, A., Montañana-Olaso, E., & Larkin, P. (2017). Nursing preparedness for practice. In M. Brenner, M. Alma, A. Clancy, P. Larkin, S. Lignou, D. Luzi, ... M. Blair (Eds.), *Report on needs and future visions for care of children with complex conditions*. Brussels: EU Commission. Retrieved from http://www.childhealthservicemodels.eu/wp-content/uploads/20171130_Deliverable-D11-2.4-Report-on-needs-and-future-visions-for-care-of-children-with-complex-conditions.pdf
- Kamionka, S. L., & Taylor, K. (2017). *Report on requirements and models for supporting children with complex mental health needs and the primary care interface*. Retrieved from http://www.childhealthservicemodels.eu/wp-content/uploads/2017/07/20171130_Deliverable-D10-2.3-Report-on-requirements-and-models-for-supporting-children-with-complex-mental-health-needs-and-the-primary-care-interface.pdf
- Keilthy, P., Warters, A., Brenner, M., & McHugh, R. (2017). *Final report on models of children's social care support across the EU and the relationship with primary health care*. Retrieved from http://www.childhealthservicemodels.eu/wpcontent/uploads/2017/07/20170728_Deliverable-D9-2.2-Final-report-on-models-of-children%E2%80%99s-social-care-support-across-the-EU-and-the-relationship-with-primary-health-care.pdf
- Lai, M., Lombardo, M. V., & Baron-Cohen, S. (2013). Autism. *Lancet*, 383(9920), 896–910. doi:10.1016/S0140-6736(13)61539-1
- Luzi, D., Pecoraro, F., & Tamburis, O. (2017). Appraising Healthcare Delivery Provision: A Framework to Model Business Processes. *Studies in health technology and informatics* 235, 511–515.
- Thapar, A., & Cooper, M. (2015). Attention deficit hyperactivity disorder. *Lancet*, 387(10024), 1240–1250. doi:10.1016/S0140-6736(15)00238-X
- Wolfe, I., Lignou, S., & Satherley, R. M. (2017). Referral–discharge interface. In M. Brenner, M. Alma, A. Clancy, P. Larkin, S. Lignou, D. Luzi, ... M. Blair (Eds.), *Report on needs and future visions for care of children with complex conditions*. Retrieved from http://www.childhealthservicemodels.eu/wpcontent/uploads/20171130_Deliverable-D11-2.4-Report-on-needsand-future-visions-for-care-of-children-with-complex-conditions.pdf