

Supporting children who have a parent with a mental illness in Tyrol: A situational analysis for informing co-development and implementation of practice changes

Ingrid Zechmeister-Koss

Ludwig Boltzmann Institut für Health Technology Assessment <https://orcid.org/0000-0003-3713-7580>

Melinda Goodyear

Monash University School of Rural Health

Heinz Tüchler

Ludwig Boltzmann Institut für Health Technology Assessment

Jean Lillian Paul (✉ jean.paul@i-med.ac.at)

<https://orcid.org/0000-0003-0891-7035>

Research article

Keywords: mental illness, children, situational analysis, context analysis, implementation science

Posted Date: October 5th, 2019

DOI: <https://doi.org/10.21203/rs.2.15578/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License. [Read Full License](#)

Version of Record: A version of this preprint was published at BMC Health Services Research on April 19th, 2020. See the published version at <https://doi.org/10.1186/s12913-020-05184-8>.

Abstract

Background: A research project aimed to improve the situation of children of parents with a mental illness (COPMI) has recently begun in the Austrian region of Tyrol. The project aims to strengthen formal and informal support structures around the child through enhancing their village of collaborative support. Understanding the current situation in the region is vital for implementing practice change. This paper aims to gain knowledge on the Tyrolean societal and service provision context.

Methods: We collected qualitative and quantitative data on overall societal characteristics, epidemiology of mental illness in Tyrol, services that currently exist within adult mental health care and for supporting children, parents and families, uptake of services, and current practices and challenges of identifying and supporting COPMIs. We analysed data along several external context dimensions: 1) professional influences, 2) political support, 3) social climate, 4) local infrastructure, 5) policy and legal climate, 6) relational climate, 7) target population, 8) funding and economic climate.

Results: While there is awareness of challenges related to COPMIs at professional and planning level, there is a lack of installed support processes and standards to meet their needs across Tyrol. A variety of services are available both for unwell parents, as well as for families and individual family members. Yet, only one small service addresses COPMIs directly. Services fall into different sectors (education, health, social affairs) and are funded from different sources, making coordination difficult. Access varies from universal to rather restricted (i.e. through referral). The potential number of parents to be reached via adult mental health, in order to identify their children, differs considerably by setting. Societal structures indicate that the informal and voluntary sector may be a realistic source for supporting COPMIs in Tyrol.

Conclusions: The societal structures and the current services provide a rich resource for improving identification and supporting of COPMIs, however considerable coordination and behaviour change effort will be required due to the fragmentation of the system and professional cultures. The insights into the context of supporting COPMIs have been of high value for developing and implementing practice changes in the local organizations.

Introduction

Research has shown that approximately 25 % of children worldwide live with a parent who has a mental illness [1–5]. These children have an increased likelihood to experience additional adversities due to their family circumstances which may lead to negative long-term emotional difficulties in some of them, alongside substantial lifelong impacts for individuals, governments and the wider community [6, 4, 7–11]. The children often remain invisible to the society or professional services because significant barriers hinder their early identification, especially in the (adult) mental health and social care settings [12–14]. Consequently, children's needs often remain unmet, and they may not have the opportunity to access support. The situation can be further exacerbated due to limited coordinated and collaborative care, which could otherwise enhance the provision of formal and informal support for children and their families [15].

We address this situation in our research project, 'How to raise the village to raise the child? Supporting children who have parents with a mental illness in Austria', seeking to improve child wellbeing outcomes for children of parents with a mental illness [16]. We focus on early identification and the enhancement of formal and informal support networks around the children and their families in the Western Austrian pilot region of Tyrol, thus focussing on early intervention, based on evidence that early intervention can work [17–19]. We approach this through the evidence-informed co-development (together with stakeholders), implementation, and evaluation of two practice approaches to improve identification of children via parents in adult mental healthcare, and strengthening child-focused support networks. Underpinning these practices are principles of child empowerment and participation, the 'child's voice', strength-based approaches, and collaborative care. For installing the support network, informal support sources should be activated as a primary source supplemented by formal support where needed. The four year project is implemented by an international and interdisciplinary research team.

According to the definition by Craig et al. (2008 and 2019) [20, 21], the practice approaches that are planned to be implemented can be defined as a complex intervention: (1) There are a number of interacting components, (2) there is a certain degree of difficulty of behaviours required by those delivering or receiving the intervention, (3) a high number of groups or organisational levels are targeted by the intervention, (4) there are a number of different outcomes, and (5) a degree of flexibility or tailoring of the intervention exist (p. 2). It has been argued that those type of interventions may unfold differently in different contexts [22] and replicating them in different jurisdictions without modifying according to context often leads to disappointing results [23]. Evidence from complexity and implementation science strongly suggests that external factors governing practice within the service context may be a major driver or barrier for successful implementation [24–26]. Consequently, a good understanding of current practice, service utilisation and the existing needs in the pilot region Tyrol is a pre-condition for developing and implementing the practice changes that are related to improved identification and support for children who have a parent with a mental illness. Furthermore, understanding the context is an important step in developing logic models of the practices changes [27] which is another important part of the co-development process in the project.

The aim of this paper is to summarise the results from a multi-dimensional situational analysis in order to obtain an in-depth understanding of the local context and the existing needs for supporting the affected children and their families. The aim of this process is to understand the local

context to feed into the design of the subsequent co-development process of the practice approaches.

Method

Figure 1 visualizes the conceptual framework for the situational analysis. Watson et al. (2018) [24] recently developed a conceptualization of the external context influencing implementation based on a literature review on empirically observed external context factors. This framework was chosen to structure the analysis of the current situation in our pilot region. The taxonomy consists of eight context constructs (see Table 1): (1) professional influences, (2) political support, (3) social climate, (4) local infrastructure, (5) policy and legal climate, (6) relational climate, (7) target population, (8) funding and economic climate [24, p. 6].

To describe the eight context constructs in Tyrol we collected empirical information on five domains: (a) the epidemiology of mental illness in Tyrol, (b) the uptake of mental health services, (c) the current practices and challenges of identifying and supporting the affected children, (d) the overall societal characteristics (demographic, socio-economic and cultural dimension), and (e) the services that currently exist within adult mental health care and for supporting children, parents and families as a whole.

As empirical material we used one primary data and a variety of secondary data sources: The primary data were interview transcripts from 17 semi-structured qualitative interviews that were conducted with expert stakeholders in Tyrol who work in different sectors and either actively work with families, parents or children or at the planning level. Two of them were people with lived experience. The interviews addressed the current practice for supporting the children and their families as well as required workforce changes and barriers to overcome. They were conducted to prepare the co-development and implementation process. Findings addressing the aims of this current paper are included. The interview guide used is available in the supplementary file 1 and has so far not been published elsewhere.

Secondary data sources included published statistics and papers (identified by hand search) as well as administrative data. The latter was provided by the core social health insurance fund in Tyrol (Tyrolean health insurance), covering 80 % of Tyrol's population (through their employer). The administrative data cover a range of essential mental health benefits: hospital inpatient, day care and inpatient rehabilitation services according to an ICD-10-F diagnosis, outpatient psychiatrist specialist services (adult as well as child/adolescent specialists), psychotherapy services, psychological services, prescribed psychotropic drugs and sick-leave according to an ICD-10-F diagnosis.

The data sources were used in the following way: The analysis of overall societal characteristics was based on descriptive statistics of published key socio-demographic and socio-economic indicators. The regional epidemiology of mental disorders and the mapping of currently existing services was informed by published literature as well as by an administrative data analysis. For the mapping, we clustered available services into those for parents with a mental illness and those for supporting children and / or families regardless whether or not they specifically target children who have parents with mental illnesses. We mapped available in-kind as well as cash benefits whereby the latter refers to monetary transfers within the health and social care system that Tyroleans may claim. The rationale was to obtain a broad understanding of the current service patterns and to identify all types of services that may be potentially relevant in the identification and support of children who have parents with a mental illness (target groups, eligibility criteria, geographical distribution, financing and governance structures, etc.). Information on current practice barriers and needs for identifying and supporting our target group was derived from the interviews. For analysing the uptake of mental health services, we analysed the administrative data described above.

Regarding the empirical method of data analysis, statistical methods applied in analysing quantitative data were mainly descriptive, including counts, percentages, and ranges, depending on the type of data. The qualitative data from local stakeholder interviews were deidentified, transcribed, and analysed using iterative inductive content analysis to generate the major themes [28]. Interviews were transcribed verbatim and translated to English and German, and double coded by at least two members of the research team using QSR International NVivo (version 12) [29]. The research team met on several occasions to discuss themes and reach consensus.

Results were identified in each domain from Figure 1 from one or more sources and will be presented according to the framework in Table 1. Quotes will be presented to support interpretations. In cases where the interviews were conducted in German, quotes were translated whereby we tried to maintain the intention as much as possible, which may possibly be at the expense of correct grammar.

Results

(1) Professional influences

Practitioners interviewed from a wide variety of fields highlighted an unmet need for the children to have support to manage the impact of mental illness in their lives. It became apparent that participants described many challenges children might face in these circumstances, but were unsure how they could support them in their professional role.

„I already had the impression that many requests were from the parents or then separated parents who are mentally ill, who were asking to get some offers or support for the children, but we simply have no offers“ (Interview 4)

„I think the situation for children with parents with psychiatric illness is not easy because there are no specific services for them. This is my general view.... I mean we see this problem but we do not know how to support the children“ (Interview 7)

In adult mental health care there is a lack of routine identification of parents and their children, other than to check on the care arrangements for a child when a parent is hospitalised.

“My impression and my knowledge is that it [whether patients have children] is very rarely asked and that it depends on whether someone is interested or not. I mean, if a doctor who has children of her own, she might - so, I'm just assuming from experience now - ask, do you have children? But it is not a standard.” (Interview 14)

„It's [asking about about children] not part of the system.... It's not standard and maybe we could develop a standard as part of the project.” (Interview 1)

Services outside adult mental health also show relatively poor guidelines and a lack of standardisation of documentation protocols to support the children themselves. Various reasons are given as to why practitioners do not ask about children or the family circumstances of the person with a mental illness: lack of sensitization of practitioners to the topic, poorly addressed topic in medical training, uncertainty on how to ask and a lack of time in the daily routine of a psychiatry.

“I think that it [asking about children and family circumstances] remains the biggest challenge in this whole subject area. It often is simply still too little information there and great uncertainty in handling it and IF and HOW to address it, that is simply still difficult.” (Interview 8)

Importantly, while individual professionals have started to introduce a more family-focused care philosophy, supporting the parent in their parenting as a core principle of care has not been implemented as care standard—and participants believed that there is a lot of shame that can be harboured by families in this area.

“The context of taking care of the children is one thing, but what I do notice, what exists even less is a systematic support of the parents in relation to this topic, parenting and this whole topic of guilt and support possibilities of the parents.” (Interview 12)

(2) Political support

The mapping of the Tyrolean situation revealed several self-help associations and programs who have a focus on mental health. Some are nationwide with regional groups in Tyrol, while others are Tyrol-specific. [30, 31]. One directly targets relatives of people with mental illnesses. However, during the interviews, it became apparent, while they often deal with individual cases involving children who have a parent with a mental illness, the interest group has not achieved system changes that would improve the situation of dependent children who have a parent with a mental illness.

“We advised relatives what they could do with the children. But we didn't accomplish ... that we from our self-help association achieve something very concrete for the children. I'm still sorry today.” (Interview 14)

The mapping exercise also demonstrated that within public administration at the regional level a mental health coordinator function exists employed by the Tyrolean government. This may play a role in supporting workforce development on the regional governmental level. Mental healthcare coordinators develop and coordinate patient-oriented mental healthcare and provide care for people with addictive disorders. Services cover outpatient and inpatient care, rehabilitation and psycho-social services, prevention and self-help activities. Additionally, the coordinator organises a steering committee including Tyrolean psycho-social care providers and advises regional government and Tyrolean hospital fund. Yet, the topic of supporting children who have a parent with a mental disorder has not been systematically addressed at the strategic level so far.

Yes, it [the topic] comes up because it can be said that vulnerable children and young people who are in contact with the psychiatric landscape usually have social problems, anomalies, homelessness, alcoholism or violence and so on in the background. It [the topic] comes up all the time. But it's not a priority right now.” (Interview 1)

(3) Social climate

Since one key component of our intervention is to activate informal care to support the children [16] the social capital of our pilot region may play a crucial role for implementation. Considering demographics and socio-economics within Tyrol, the region can be classified as traditional and conservative in relation to family formations and characteristics of education/employment [30]. For example, from around 140,000 dependent children between 0 and 18 years (19% of the Tyrolean population), the vast majority live in dual-parent families [32, 33]. Additionally, there was a slightly higher number of children per household than the Austrian average [32]. 30% of the employees are working part-time, the majority of them are women [34]. In 2016/2017, most children were cared for at home, with only 33% of children aged 0 to 14 years were using child care in Tyrol [35].

The traditional gender roles are also expressed in the interviews. When interviewees reflected on current needs, support needs are primarily identified for mothers (“...and especially the sick parents need support and especially the mothers”/ interview 14) while fathers are not mentioned at all (“they

[outreach services] can support above all the mothers (..) in their educative ability / interview 14”).

However, a difference between rural and urban areas was described

Here it is even more archaic - archaic mechanisms are still in progress. There are also many large families here. I think that for many generations - dealing with problems, feelings, women's dedication to the family and such things. These are still very, very much more pronounced here than, for example, in the city (interview 12).

Regarding religion, a catholic denomination plays the most important role in Tyrol (~80 % of population) [36]. The political history shows that the conservative people's party has always had an absolute or relative majority in the regional government [37]. Eighty-five percent of Tyroleans are Austrian citizens. While there is a Turkish community and people from South-Eastern European countries living in Tyrol, the largest groups with non-Austrian nationality are Germans with similar cultural background [38].

(4) Local infrastructure

We identified a broad range of potentially relevant services for identifying and / or supporting affected children (Figure 2) [30]. The core services for identifying the children within the project scope are adult mental health services. They include a large variety of services (hospital and outpatient as well as psycho-social, employment-related and inpatient rehabilitation services) and are provided in various settings. Services beyond adult mental health care, which may also play a role for improving identification of the children in Tyrol, include the 'Early Prevention Service' for pregnant women and families with children up to three years (Frühe Hilfen), a screening program in pregnancy and early childhood (Mutter-Kind Pass), primary healthcare services, or services provided by specialists in schools including school psychologists, school social workers, or school physicians.

Following identification, services belonging to child and youth welfare field may all be potentially relevant in supporting the children and families in their daily life. Additionally, there are a number of social services offering support for children and/or families which could be utilised by children of parents with a mental illness (e.g. adolescents/youth centres with specific meeting areas, coaching for adolescents, and specialised support for girls). In addition, a number of services have been identified that offer parenting support. These services could be used for parents with a mental illness to support them in their parenting roles. As has been mentioned earlier, there are activities within the informal sector, most significantly, self-help groups specific to mental health (e.g. self-help groups for family members of people with mental disorders), but also further initiatives in the voluntary sector such as host grandmothers. Out of all services that may be potentially relevant for supporting the children, there was only one service ('Kinderleicht') identified which specifically addresses children of parents with a mental illness, more specifically, children of parents with addictive disorders. However, this service is relatively small and at this stage, only available within two regions in Tyrol.

Besides in-kind services, cash benefits have been identified which could be used by families impacted by mental illnesses. Importantly, cash benefits were identified which are Tyrol-specific and accessible in an emergency situation or for low-income families (e.g. 'Kinderbetreuungszuschuss des Landes Tirol' providing opportunities for child care).

While there is a broad variety of services available, some obvious gaps in the care pathway for the children have also become apparent. This is for example the case in emergency situations where individual solutions have been described to bridge the gap between time of admission and opening hours of child and youth welfare offices.

"And sometimes we had the problem, especially during the nights. We knew there was a child at home and nobody can care for this child right now. And then we have to get in contact with the Department for Paediatrics, not psychiatry unit but the normal clinic, asking "Do you have a bed only for one night? We need a place for this child. We don't know what to do now. There is nobody else who can care for this child now. Could you please take this child for one night?" But, also this is a very bad situation. I mean the child is very embarrassed about this situation, that somebody else comes at home again, takes the child, to come to the clinic and go there knowing nobody, only have to sleep here tonight, we'll care tomorrow, when the institution is working again and we will find a place for you." (Interview 7)

Additionally, more types of services were available in urban than rural regions, demonstrating geographical variation.

(5) Policy and legal climate

Two policies at the national level (both launched in 2012) were identified that may be utilized for implementation of the planned practice approaches in Tyrol. Firstly, the Austrian child and adolescent health strategy includes five strategic goals, which are all addressed by the planned practice approaches: improve equal health opportunities, strengthen and maintain individual health resources, support healthy development early on, reduce health risks, raise awareness for health in all policies [39]. Secondly, several out of the ten Austrian health targets [40] are closely linked to the planned practice approaches and the envisaged impact. For example, the practice approaches in the Village project target aim number five (to strengthen social cohesion as a health enhancer), particularly outlining the importance of social relationships and social networks, which will be addressed by the project's aim to activate the social support network around the child. Furthermore, they also target aim number six (to ensure conditions under which children and young people can grow up as healthy as possible), thus addressing our target group directly; and target aim

number nine (to promote psychosocial health in all population groups). In addition to tackling stigma, it is outlined that “people suffering from mental disorders, and their relatives (especially parents and children) need comprehensive, appropriate care services, and their (re)integration into society must be assured [40, p. 15].”

(6) Relational climate

The services identified are legally assigned to different welfare state sectors. Most of identified existing services for parents with a mental illness are provided within the realm of the health care system. However, the majority of significant services for family, children, or parental support for their everyday life lie within the education or social affairs sectors. Consequently, families and service coordinators are confronted with a complex service financing system, whereby responsibilities can be born by governments at federal, regional, or municipal level, or by the health insurance company, or a combination of these (Figure 3). Regional government responsibility is central for many core services identified supporting children's daily life. This suggests that it will be important to consider local politics in relation to implementing changes within existing practice. Furthermore, compared to health services, funding of those social services is frequently 'project based', therefore subject to discretionary decisions [30].

Having a broad variety of services and their complex governance and financing structures makes not only coordination challenging, but also the provision of individual and needs-based support becomes difficult.

“We have noticed that when more than two organizations work in a family, it can cause more confusion than it helps. Because families have in the organization of their everyday life, here this offer, there that offer, here this... “They say they only do this, they are only responsible for that, but when need something, which perhaps needs a little bit of both, then I am back again. I may need a third organization.” That is the great difficulty, in our view, in supporting the families.” (Interview 2)

(7) target population

The available data do not allow identifying precise numbers of affected children or parents with a mental illness. Furthermore, robust epidemiological data on the mental illness in Tyrol are lacking. However, the administrative data analysis [41] showed that ~ 50,000 insured persons aged 19–64 years (13 % of the insured population) received some type of Tyrolean social health insurance (co)-funded mental health benefit. From those potential parents with a mental disorder, overwhelming, most were prescribed medication (82%), half of whom received exclusively medication, without accessing other types of insurance funded services (Figure 2). General practitioners prescribe more than 90% of psychotropic drugs in Tyrol [42]. People were most frequently prescribed anti-depressants (61%), followed by anti-psychotics (18%). Other types of psychotropic drugs were prescribed to less than 10% of patients. Forty percent of the 19–64 years old potential parents accessed some type of insurance-funded 'physical' service in 2017 for mental health (covering the hospital, outpatient services, or rehabilitation services). Services most frequently used were outpatient psychiatric services, accessed by over a quarter of this group, whereas only 7% were admitted to hospital inpatient or received day-care treatment (Figure 4).

A higher percentage of female insured persons aged 19–64 years used mental health benefits than male insured. This gender difference is particularly apparent for use of medication, outpatient psychotherapy and psychiatrist specialist services, whereas the proportion is almost equal regarding hospital (inpatient and day care) services (Figure 5).

Regarding hospitalised patients, the most frequently documented diagnoses were F1 (mental and behavioural disorders due to psychoactive substance use), F3 (mood [affective] disorders) and F4 (anxiety, dissociative, stress-related, somatoform and other non-psychotic disorders), whereby F1 was documented considerably more often in males than females, and F3 as well F4 were more frequent in female patients. Length of stay in hospital admissions varied considerably (range: 1 to > 300 days), however, 50 % were discharged after 15 days. Furthermore, 50 % of the patients were only admitted once during 2017 and a quarter of the patients were admitted in non-psychiatric wards (mostly internal medicine wards). No information is available on the frequency of use in services that are funded by other payers (e.g. psycho-social services which are funded out of regional taxes) or on the frequency of hospital outpatient service use.

Expert interviews with service providers and people with lived experience revealed a number of barriers to families seeking help. There is commonly a burden of care on these children, but also secrecy and fear are paramount within these families.

“The problem is ... that the usual taboo mechanisms in families are still practiced. The problem is often in adult psychiatry the tendency is, in my experience, not to involve family members or the patient's environment in that way. The parent, or even the children, to address this topic. Because, what I think is, that this is a taboo to talk about and promises difficulties. Yes. This is, of course, an extremely shameful story. Not to carry out the parental role, or to have harmed the children or such things...” (Interview 6)

A fear associated with child and youth welfare is a major barrier to families talking about their child in adult psychiatry. Stakeholders describe patients being reluctant to mention in the psychiatry settings that they are parents or do not speak about the impact of the illness on parenting, as they are afraid that the psychiatry department could contact the child and youth support and they could then remove the children.

"They keep saying child and youth office, although we are now called child and youth welfare, because it is the office that somehow has the bad taste that takes the children and never gives them back and so on. The barrier for mothers to go to child and youth welfare is often high." (Interview 5)

Available services in Tyrol are characterised by a high proportion of public funding. However, access to many of these publicly funded services is constricted via gate-keeping (e.g. particularly depending on referral from child and youth service) [30] or limited capacities of services (e.g. psychotherapy, childcare) [43]. Furthermore, many services are reserved for families and children with severe problems. Yet, it was also pointed out that not all families need professional intervention to help them manage the impact of mental illness, and professional support was even considered to be potentially harmful in cases where the children are healthy.

"Certainly, a third [of children] can arise relatively quickly from one's own resources, i.e. where one can activate something in the family, something that has not been considered so far. A third, where you simply have to act a little more intensively, so that something happens. More or perhaps less a third is where you really say, "It really needs interventions now, there really is suffering among the children", i.e. perhaps roughly 20%, where I really say, it needs professional help. That is certainly not the case with all." (Interview 13)

"I am very concerned that these healthy children - for me these are healthy children - are diagnosed too quickly and receive some care too quickly, which may not be necessary for many. If the children experience a lot of normality and good social relationships in addition to the stress in the family, they can develop quite well and stay healthy. If they get diagnosed too soon, it means for them you're not okay. Something's wrong with you, you need something." (Interview 14)

(8) Funding and economic climate

The availability of funding for the children is strongly interwoven with the system of social security. The Tyrolean system of social security is an integral part of the overall Austrian welfare state structures, which characterized by a high degree of public intervention and social protection mechanisms [44]. However, social services are closely aligned with achievements through gainful employment. In 2014, spendings on public social welfare benefit accounted for in excess of 30% of annual economic value added. Healthcare comprised one quarter of total welfare spending, while another 9 % (€ 9.2 bn in 2014) was on families. The proportion of spendings on social exclusion and housing was, however, only 2 % [44]. The largest proportion of the family benefits was spent on cash benefits. Some identified cash benefits, such as family allowances, tax credits for childcare and childcare allowances, are universal transfer payments, meaning that they are independent of gainful activity and income. Other types are however dependent on employment and income (maternity allowances around childbirth), while a third category of cash benefits is means-tested, meaning that eligibility is linked to specific needs in the absence of own economic resources. Compared to international benchmarks, expenditure for in-kind benefits (e.g. subsidies for childcare facilities or family services) is low in Tyrol, in comparison to cash-benefits [45]. The regional and local governments are the key providers of in-kind benefits. Their expenditure totalled €2.5 bn in 2014 [44].

In Tyrol, no data are available on overall spending on mental health care. However, findings demonstrate the capacity of publicly funded services is more likely to be restricted in the mental health area compared to physical health services. Consequently, patients with a mental illness more likely face private out-of-pocket payment. For example, there is a low number of child and adolescent psychiatrists who hold a contract with the health insurance in the outpatient sector in relation to need. Likewise, access to publicly funded psychotherapy services is restricted due to limited capacities and patients often need to contact a private therapist. Limited availability to services is particularly noted for child and adolescent mental healthcare [53–55].

Discussion

In this paper we aimed to develop a deep understanding of the situation facing children with a parent with a mental illness in Tyrol, Austria, in terms of identification and support. This knowledge was used to inform the next steps of the project, which are to design the co-development process for developing the practice approaches together with local stakeholders and to implement the practices in the local organisations. The conceptual matrix by Watson et al. [24] has been used to systematically identify external context factors that may influence the co-development and implementation process.

While the precise prevalence of parental mental illness and their children in Tyrol remains unknown, benefit uptake data demonstrate that a substantial number of parents may be reached via the primary health care system (e.g. the general practitioner), and only 5% via psychiatric secondary care (inpatient hospital setting). However, those in inpatient care could be considered the most severely ill parents, whose support needs for themselves and their children may be consequently be higher. Furthermore, the results suggest that more mothers than fathers with a mental illness will be possibly reached via adult mental health care overall, while the gender-difference is less pronounced in the hospital setting.

Although Austrian public expenditure for families and children could be considered as generally high compared to other countries [45], the data have shown that there are hardly any services available that target children who live with a parent with a mental disorder specifically. One reason may be that the largest share of family expenditure are cash benefits rather than benefits in kind. However, among the existing services there is a potential

of professional resources and an array of services available that may be accessed and coordinated for addressing different types of needs individual children may have. To some extent specific cash benefits that are available in Tyrol may serve as an additional resource of support. Yet, while this variety offers flexibility for organising individualised and needs-based support, considerable challenges for coordination and organising individualised support could be faced due to various funding and legal arrangements. Importantly, several services may have limited access for families due to referral pathways or geographical variations. Many services for children are restricted to children having problems already, while our approach focuses on low-threshold early intervention where existing services are inappropriate or not accessible for our target group of healthy children. Targeting healthy children may in the long run reduce child and adolescent hospital resource use or resources required for special school support which has been shown as being higher for children who have parent with a mental disorder than for children with parents who are mentally healthy [11]. Because potentially relevant existing services or new services for supporting the children are likely part of the social sector, stable and sufficient funding seems to be difficult to achieve under the current legal and funding conditions. A facilitating factor for the successful and sustainable implementation of the planned practice approaches seems therefore to be to integrate them into existing the routine processes (e.g. integrating identification of children into the routine assessment of patient admissions in adult mental health), rather than creating new services that may not have sustainable funding beyond the duration of the project.

Furthermore, at the level of professionals and the target population barriers that may have to be overcome are fear and limited help seeking among affected parents and / or their children as well as shame to address the topic of parenting in both, the parent with a mental illness and the treating professionals. This will have to go in line with critically addressing structural and legal conditions that fuel those fears. Furthermore family-focused care philosophy and parenting in general has so far not been part of the treatment concept in a standardized form in adult mental health and thus, professionals may need support to engage in these conversations with parents in a safe and non-judgemental way.

As has been outlined in the introduction, our support concept focuses on mobilising and utilising informal resources around the individual children/families before more formal and professional support is sought. Accordingly, our data indicate that while all children affected may need general support during episodes of their parent's mental illness, a proportion of children are otherwise healthy and do not necessarily need professional care. Parameters for demography and socio-economics identified in our analysis indicate that Tyrol is a conservative region in terms of family composition and education/employment characteristics. Therefore, informal supports and a community system could still play a big role in everyday life for families in this region (e.g. fewer resources for childcare than in other parts of Austria [46], high rate of part-time working females, Catholic tradition). Not least, we identified a number of activities within the voluntary sector (e.g. self-help groups) which could be potential resources for families. This implies that it may be feasible in our pilot region for families and children to utilise informal resources for support alongside more formal support structures. However, stigma and secrecy could be more challenging than in regions with more progressive character. The Austrian health targets as well as the child and adolescent health strategy may be utilized at the national policy level to foster implementation of the practice approaches, however, at the regional level political backing is less pronounced and the topic has not been defined as an explicit strategic goal at the administrative planning level so far.

Contextual information collected and analysed are likely to be incomplete within this work and is a limitation: The published data used for mapping the services may not represent changes in the service infrastructure that may have happened after the publication dates. Additionally, there are some limitations related to administrative data used regarding diagnostic validity of the information and they do not cover the full range of mental health services available. However, our results and the data collected were reviewed by regional experts and the findings were presented to an open forum for comments. Recruitment of participants to be interviewed was based on the mapping of services, where we attempted to represent all the service settings as well as people with lived experience. However, we had limited number of participants per sector, which may have limited the diversity of views within these sectors. That said, we found common themes across the interviews. As the authors of the applied conceptual framework on the external context note, the conceptual matrix may not cover all aspects of external context (e.g. physical environment such as topography) and the categories are not entirely mutually exclusive [24]. While we gained valuable insights into the current situation by this systematic approach, the context information may therefore to some extent still be incomplete.

The information from the situational analysis was fed into the next step—the design of the co-development process—in different ways: Firstly, it was used to construct a conceptual map of service sectors and structures, which was then applied to select key stakeholders from each sector, level of care and professional groups in order to achieve maximum diversity of participants in the co-development workshops. Secondly, it was used to construct vignettes describing the current situation of affected children in Tyrol to be used by the workshop participants for identifying key areas of change. Thirdly, it drove pre-selection of international practice approaches and evidence-based interventions that would be potentially feasible in the Tyrolean context. Finally, it was used to refine the theory of change and logic model (a formal and explicit articulation of the assumptions that underpin the rationale and design of the practice) that were developed alongside the workshops to demonstrate the link between context, mechanisms and outcomes of the envisaged practice approaches.

Conclusion

Identifying and supporting children who have a parent with a mental disorder in a standardised way can be defined as complex intervention. For developing specific practice approaches and successful implementation in our pilot region, extensive context knowledge is required. The systematic analysis of the external implementation context showed that key stakeholders are aware of unmet needs and that the societal structures and the

current services provide a rich resource for improving identification and supporting of the children, however considerable coordination and behaviour change effort will be required due to the fragmentation of the system and professional cultures. The insights into the context of supporting the children have been of high value for designing the co-developing process during which researchers, practitioners and people with lived-experience are jointly developing practice approaches for their specific organisations in order to improve the situation for affected children and their families.

List Of Abbreviations

COPMI - Children of parents with a mental illness

ICD - International classification of diseases

GDP - Gross domestic product

Declarations

Ethics approval and consent to participate

The qualitative interviews have been approved by the Monash University Human Research Ethics Committee (MUHREC).

Project Title: Understanding practice challenges to supporting children of parents with a mental illness in Tyrol, Austria

Project Id: 14093

Written informed consent has been provided by all interviewees.

Consent for publication

Not applicable

Availability of data and materials

The interview datasets and the administrative datasets generated and/or analysed during the current study are not publicly available due to privacy and data protection law reasons.

The national and regional statistics as well as published materials used for the paper are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

The paper was written as part of a 4-year research project “The Village” funded by the Austrian Federal Ministry of Health - Science and Research through the Open Innovation in Science Centre at the Ludwig Boltzmann Gesellschaft GmbH, hosted at the Medical University of Innsbruck, with collaboration of Co-Investigator institutions. The funders did not influence the collection, analysis, and interpretation of data and played no role in writing the manuscript.

Authors' contributions

IZ processed the administrative data used in the paper, analyzed the published service mapping data and the public statistics. Additionally, she undertook the conceptual analysis based on the context constructs and conducted most of the qualitative interviews. She produced the first draft of the manuscript. MG conducted parts of the interviews and analyzed and interpreted the qualitative interview data. HT statistically analyzed and interpreted the administrative data regarding benefit uptake. JP analyzed and interpreted the qualitative interview data. MG, HT and JP co-drafted the methods, results and discussion sections. All authors read and approved the final manuscript.

Acknowledgement

Special thanks to thank Anna-Elena Pinggera, Julia Kapferer, Johanna Krönner and Elena Seis for their support in holding, transcribing and analysing the interviews, to Rosanna Buchauer for the coordinating work, to Katharina Hintringer and the Tyrolean health insurance for providing the administrative data and for supporting us in correct interpretation, and to experts from the Tyrolean local government (Karl Stieg, Gertrud Gaugg) who reviewed the service mapping data. We would like to thank all interview participants and individuals who provided comment to earlier reports at our open forum. Furthermore, we would like to acknowledge the creators of the symbols in figure 2 and 3: J. Wilson, Hans, Fahmioline, N Tatah, M, Curey, E. Kang, V Faisloyer, M Fusilio, M Thompson, V. Market, F. Vier, L. Prado (<https://thenounproject.com/>).

References

1. Test MA, Burke SS, Wallisch LS. Gender differences of young adults with schizophrenic disorders in community care. *Schizophrenia Bulletin*. 1990;16(2):331–44.
2. Fraser C, James EL, Anderson K, Lloyd D, Judd F. Intervention programs for children of parents with a mental illness: A critical review. *International Journal of Mental Health Promotion*. 2006;8:9–20.
3. Ostman M, Hansson L. Children in families with a severely mentally ill member. Prevalence and needs for support. *Social Psychiatry and Psychiatric Epidemiology*. 2002;37(5):243–8. doi:<https://doi.org/10.1007/s00127-002-0540-0>
4. Maybery D, Reupert A, Goodyear M, Ritchie R, Brann P. Investigating the strenghts and difficulties of children from families with a parental mental illness. *Australian E-Journal for the Advancement of Mental Health*. 2009;8(2):1–10.
5. Pretis M, Dimova A. Vulnerable children of mentally ill parents: towards evidence-based support for improving resilience. *Support for Learning*. 2008;23:152–9.
6. Power J, Goodyear M, Maybery D, Reupert A, O'Hanlon B, Cuff R et al. Family resilience in families where a parent has a mental illness. *Journal of Social Work*. 2016;16(1):66–82.
7. Kowalenko NM, Mares SP, Newman LK, Sved Williams AE, Powrie RM, van Doesum KTM. Family matters: Infants, toddlers and preschoolers of parents affected by mental illness. *MJA Open*. 2012;1 (Suppl 1, 16 April 2012).
8. Reupert A, Maybery D. Families affected by parental mental illness: A multiperspective account of issues and interventions. *American Journal of Orthopsychiatry*. 2007;77(3):362–9.
9. Reupert A, Maybery D, Kowalenko NM. Children whose parents have a mental illness: Prevalence, need and treatment. *Medical Journal of Australia*. 2013;199(3 Suppl):7–9.
10. Hosman CMH, van Doesum KTM, van Santvoort F. Prevention of emotional problems and psychiatric risks in children of parents with a mental illness in the Netherlands: The scientific basis to a comprehensive approach. *Australian e-Journal for the Advancement of Mental Health*., 2009;8(3):250–63.
11. Wansink HJ, Drost RMW, Paulus ATG, Ruwaard D, Hosman CMH, Janssens JMAM et al. Cost-effectiveness of preventive case management for parents with a mental illness: a randomized controlled trial from three economic perspectives. *BMC Health Services Research*. 2016;16(228). doi:DOI 10.1186/s12913-016-1498-z.
12. Falkov A, Goodyear M, Hosman CMH, Biebel K, Skogøy BE, Kowalenko N et al. A systems approach to enhance global efforts to implement family-focused mental health interventions. *Child and Youth Services*. 2016;37 (2):175–93.
13. Goodyear M, Hill TL, Allchin B, McCormick F, Hine R, Cuff R et al. Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness. *International Journal of Mental Health Nursing*. 2015;24(2):169–80.
14. Goodyear M, McDonald M, von Doussa H, Cuff R, Dunlop B. Meeting the Intergenerational Needs of Families Where a Parent Has a Mental Illness. *Journal of Parent and Family Mental Health*. 2018;3(2). doi:<https://doi.org/10.7191/parentandfamily.1011>.
15. Goodyear MJ, Obradovic A, Allchin B, Cuff R, McCormick F, Cosgriff C. Building capacity for cross-sectorial approaches to the care of families where a parent has a mental illness. *Advances in Mental Health*. 2015;13(2):153–64.
16. Christiansen H, Bauer A, Fatima B, Goodyear M, Lund I, Zechmeister-Koss I et al. Improving Identification and Child-Focused Collaborative Care for Children of Parents With a Mental Illness in Tyrol, Austria. *Front Psychiatry* 2019;10:233. doi:10.3389/fpsy.2019.00233.
17. Thanhhäuser M, Lemmer G, Girolamo G, Christiansen H. Do preventive interventions for children of mentally ill parents work? Results of a systematic review and meta-analysis. *Curr Opin Psychiatry*. 2017;30(4):283–99. doi:10.1097/YCO.0000000000000342.
18. Siegenthaler E, Munder T, Egger M. Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *Am Acad Child Adolesc Psychiatry*. 2012;51(1):8. doi:10.1016/j.jaac.2011.10.018.
19. Cuijpers P, Weitz E, Karyotaki E, Garber J, Andersson G. The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis *Eur Child Adolesc Psychiatry*. 2015;24(2):237–45. doi:10.1007/s00787-014-0660-6.
20. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*. 2008;337. doi:10.1136/bmj.a1655.
21. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions. 2019. <https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/>.

22. Jagosh J. Realist Synthesis for Public Health: Building an Ontologically Deep Understanding of How Programs Work, For Whom, and In Which Contexts. *Annual Review of Public Health*. 2019. doi:10.1146/annurev-publhealth-031816-044451.
23. Gate D. Developing theories of change for social programmes: co-producing evidence-supported quality improvement. *Palgrave Communications*. 2018;4(90). doi:DOI: 10.1057/s41599-018-0139-z | www.nature.com/palcomms.
24. Watson DP, Adams EL, Shue S, Coates H, McGuire A, Chesher J et al. Defining the external implementation context: an integrative systematic literature review. *BMC Health Serv Res*. 2018;18(1):209. doi:10.1186/s12913-018-3046-5.
25. Chambers DA, Glasgow RE, Stange KC. The dynamic sustainability framework: addressing the paradox of sustainment amid ongoing change. *Implement Sci*. 2013;8:117. doi:10.1186/1748-5908-8-117.
26. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C et al. Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. *J Med Internet Res*. 2017;19(11):e367. doi:10.2196/jmir.8775.
27. Funnel SC, Rogers PJ. *Purposeful Program Theory*. San Francisco: Jossey-Bass 2011.
28. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3:77–101.
29. NVivo qualitative data analysis software. Version 12. QSR International Pty Ltd.; 2018.
30. Zechmeister-Koss I, Goodyear M. Supporting children who have parents with mental disorders in Tyrol: A mapping of existing Tyrolean support structures. Wien: Ludwig Boltzmann Institute for Health Technology Assessment 2018.
31. Selbsthilfe Tirol. Selbsthilfe Tirol. 2018. <https://www.selbsthilfe-tirol.at/>. Accessed 19 Sept 2018.
32. Amt der Tiroler Landesregierung. Sozial-, Kinder- und Jugendhilfebericht 2015–2016. Innsbruck: Amt der Tiroler Landesregierung 2017.
33. Statistik Austria. Bevölkerungsstatistik: Familien. 2018. https://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/bevoelkerung/haushalte_familien_lebensformen/familien/index.html. Accessed 16 May 2018.
34. Statistik Austria. Mikrozensus Arbeitskräfteerhebung 2017. 2018. <http://statcube.at/statistik.at/ext/statcube/jsf/dataCatalogueExplorer.xhtml>. Accessed 20 March 2018.
35. Amt der Tiroler Landesregierung. Statistik der Kinderbetreuungseinrichtungen in Tirol 2016/2017. Innsbruck: Amt der Tiroler Landesregierung. Sachgebiet Landesstatistik und tiris 2017.
36. Amt der Tiroler Landesregierung. Die Tiroler Bevölkerung. Ergebnisse der Volkszählung 2001. Innsbruck: Amt der Tiroler Landesregierung 2004.
37. Amt der Tiroler Landesregierung. Landtagswahlen seit 1945. 2019. https://www.tirol.gv.at/fileadmin/landtag/downloads/2013/Homepage/Landtagswahlen_seit_1945.pdf. Accessed July 31st 2019.
38. Amt der Tiroler Landesregierung. Demographische Daten Tirol 2016. Innsbruck: Amt der Tiroler Landesregierung. Sachgebiet Landesstatistik und tiris 2017.
39. Bundesministerium für Gesundheit. Kinder- und Jugendgesundheitsstrategie. Wien: Bundesministerium für Gesundheit 2012.
40. Federal Ministry of Health and Women's Affairs. Health Targets Austria. Vienna: Federal Ministry of Health and Women's Affairs 2012.
41. Zechmeister-Koss I, Tüchler H. Prevalence of mental disorders and uptake of mental health services in Tyrol. LBI-HTA Projektbericht Nr. 113b. Vienna: Ludwig Boltzmann Institute for Health Technology Assessment 2018.
42. Heubacher A. 1,6 Millionen Mal Psychopharmaka in Tirol verordnet. *Tiroler Tageszeitung*. 2018.
43. Zechmeister-Koss I, Winkler R, Fritz C, Thun-Hohenstein L, Tüchler H. Services Use of Children and Adolescents before Admission to Psychiatric Inpatient Care. *The Journal of Mental Health Policy and Economics*. 2016;19:103–14.
44. Federal Ministry of Labour SAaCP. The Austrian Welfare State. Benefits, expenditure and financing 2016. Vienna: Federal Ministry of Labour, Social Affairs and Consumer Protection 2016.
45. Kammer für Arbeiter und Angestellte. Sozialleistungen im Überblick 2018. Wien: ÖGB Verlag; 2018.
46. Statistik Austria. Kindertagesheimstatistik. Wien: Statistik Austria 2018.

Tables

Table 1: Framework for context constructs

professional influences	formal or informal norms, rules, policies or standards guiding the professionalization of individuals involved in the implementation
political support	extent of backing from public officials or special interest groups
social climate	beliefs, values, customs and practices of the larger community and / or system within which the intervention is embedded
local infrastructure	physical, technical, service, and training structure or resources existing in the community or larger system in which the intervention is embedded
policy and legal climate	formal national, state, community, or system regulations (rules, policies, laws) impacting the intervention
relational climate	degree and / or quality of relationships with external entities (e.g. referral sources, partner organizations, regulation agencies, etc.) not involved in implementation but key to successful intervention delivery
target population	characteristics associated with individuals the intervention is designed to impact including population needs, culture, beliefs, preferences, locatability, ability to access, and motivation to engage
funding and economic climate	the character of the national, regional, or local economy and availability of funding as related to the intervention

Notes

Ludwig Boltzmann Institute for Health Technology Assessment, Garnisongasse 7/20, 1090 Vienna, Austria

School of Rural Health, Monash University Melbourne, Wellington, Clayton, Victoria, 3800 Australia

Mental Health Research Group Programme, The Village, Ludwig Boltzmann Gesellschaft, c/o MedUni Innsbruck, Tirol Kliniken GmbH, Schöpfstraße 23a, 6020 Innsbruck, Austria

Department of Psychiatry, Psychotherapy and Psychosomatics, Division of Psychiatry I, Medical University of Innsbruck, Anichstraße 35, 6020 Innsbruck, Austria

This paper focuses on children of parents with a mental illness who will be referred to as 'children' or 'these children' for the remaining of the paper.

For further information on the project see www.village.lbg.ac.at

F00-F09: Mental disorders due to known physiological conditions; F10-F19: Mental and behavioural disorders due to psychoactive substance use;

F20-F29: Schizophrenia, schizotypal, delusional, and other

non-mood psychotic disorders; F30-F39: Mood [affective] disorders; F40-F48: Anxiety, dissociative, stress-related, somatoform and other

nonpsychotic mental disorders; F50-F59: Behavioural syndromes associated with physiological disturbances and physical factors; F60-F69:

Disorders of adult personality and behaviour; F70-F79: Intellectual disabilities; F80-F89: Pervasive and specific developmental disorders; F90-F98:

Behavioural and emotional disorders with onset usually occurring in childhood and adolescence; F99: Unspecified mental disorder

Figures

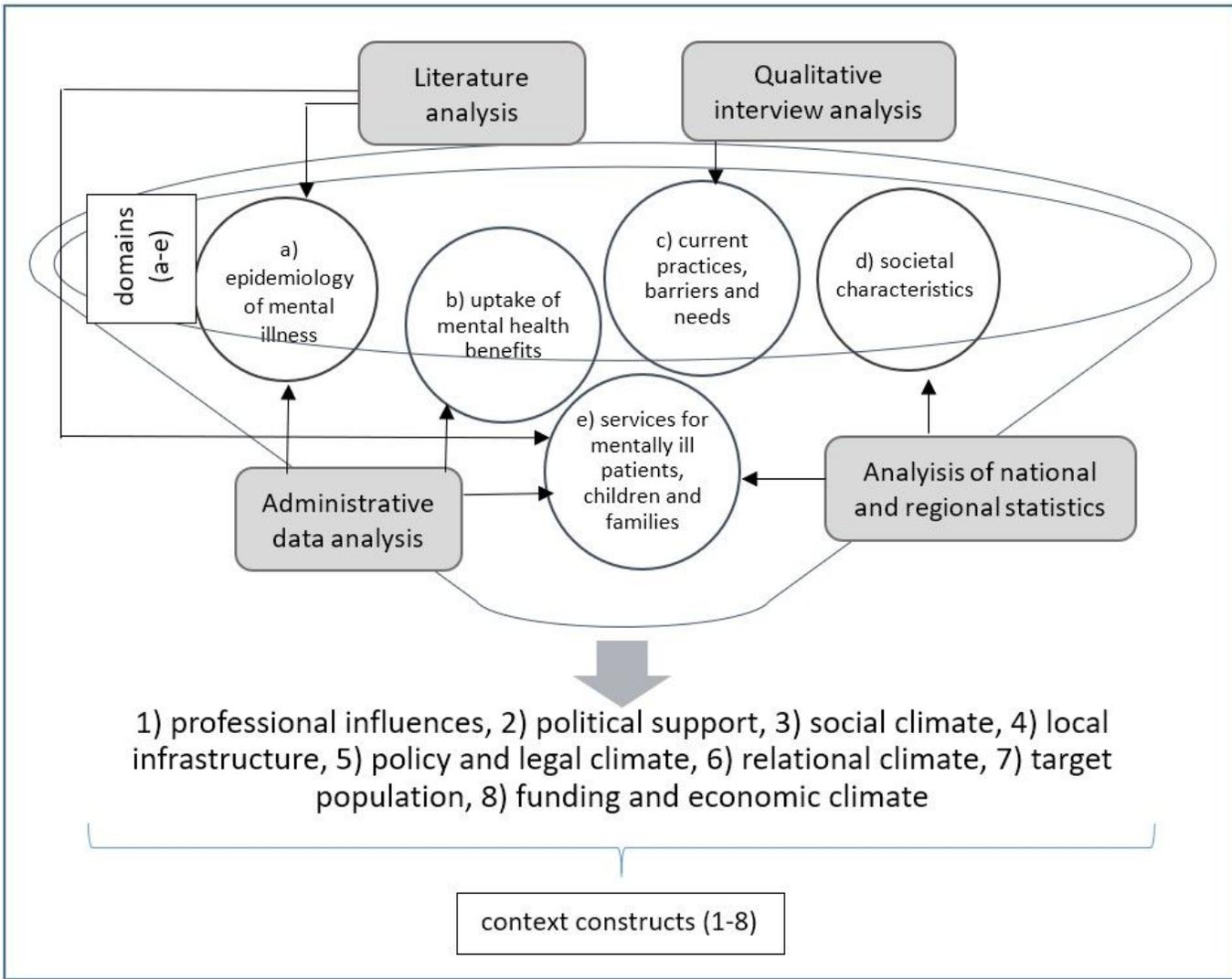


Figure 1

Conceptual framework and empirical data sources for analysis

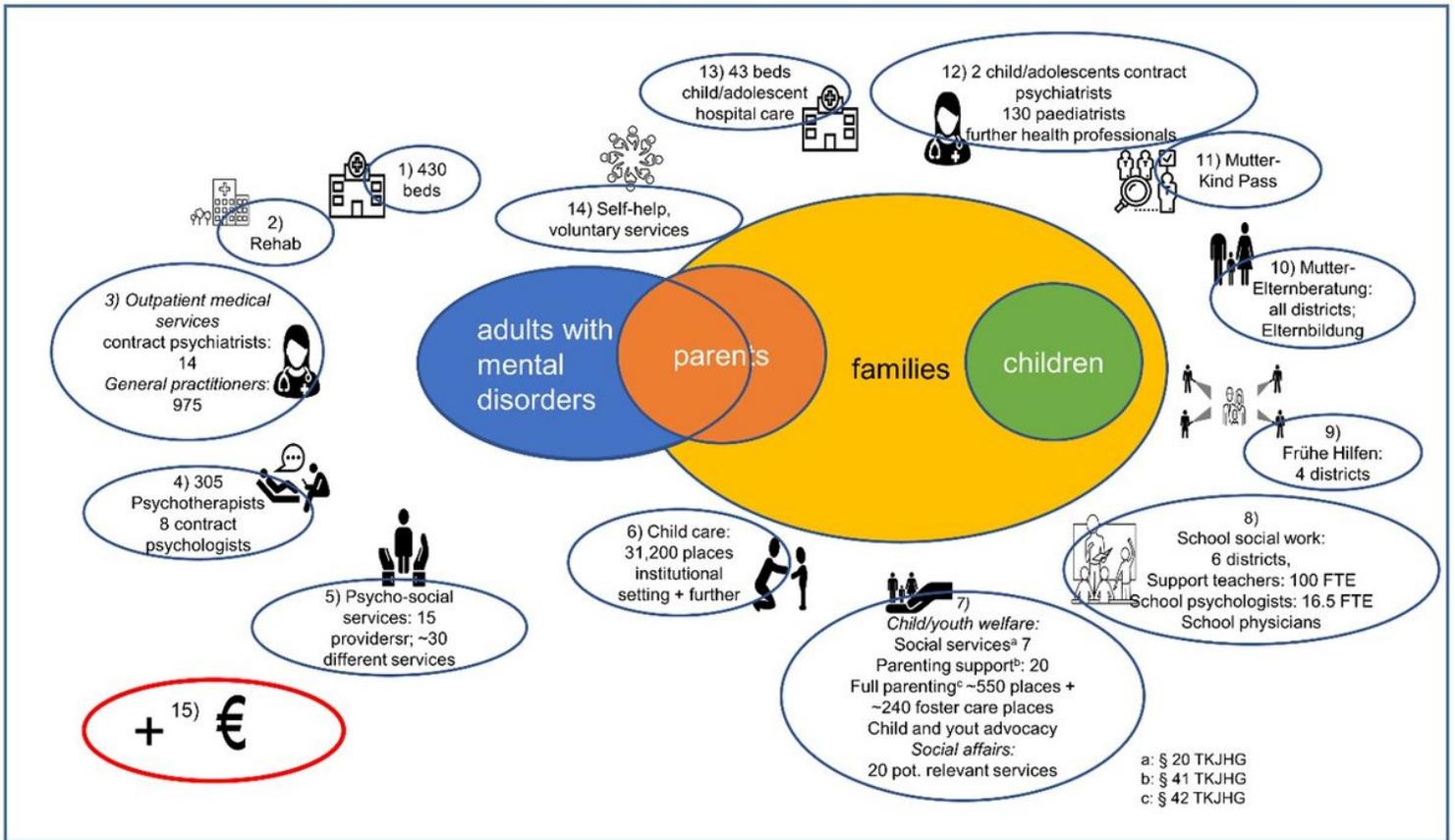


Figure 2

Overview on available services. 1: hospital services (inpatient, day care, outpatient); 2: inpatient rehabilitation, 3: outpatient services (psychiatrists, general practitioners, other health professionals such as occupational therapists, etc.), 4: psychotherapists and psychologists, 5: psycho-social services (regional government), psychological counselling (health insurance), psycho-social counselling (regional government); 6: child care; 7: child and youth welfare and social services; 8: services in schools (school social work, school physicians, school psychologists, support teachers); 9: Frühe Hilfen (early intervention in pregnancy and early childhood); 10: parental services, 11: Mutter-Kind Pass (screening programm in pregnancy and early childhood); 12: outpatient specialists for children and adolescents: child and adolescent psychiatrists, paediatrists, psychotherapists ...); 13: hospital services for children and adolescents: child and adolescent psychiatry, paediatric units; 14: self-help and services offered by voluntary workers, 15: cash benefits;

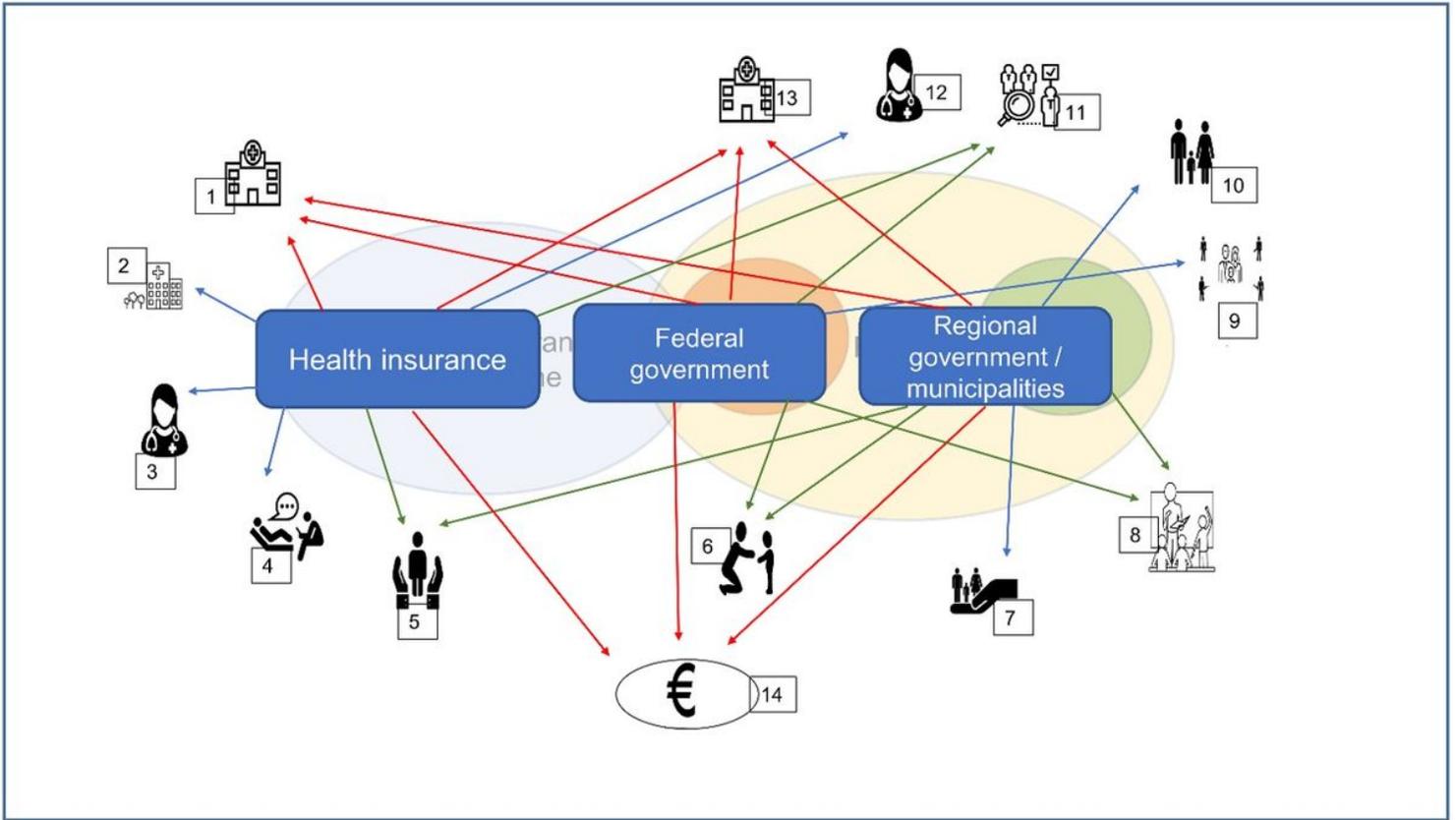


Figure 3

Financing structures for services. 1: hospital services (inpatient, day care, outpatient); 2: inpatient rehabilitation, 3: outpatient services (psychiatrists, general practitioners, other health professionals such as occupational therapists, etc.), 4: psychotherapists and psychologists, 5: psycho-social services (regional government), psychological counselling (health insurance), psycho-social counselling (regional government); 6: child care; 7: child and youth welfare and social services; 8: services in schools (school social work, school physicians, school psychologists, support teachers); 9: Frühe Hilfen (early intervention in pregnancy and early childhood); 10: parental services, 11: Mutter-Kind Pass (screening programm in pregnancy and early childhood); 12: outpatient specialists for children and adolescents: child and adolescent psychiatrists, paediatric units, psychotherapists ...); 13: hospital services for children and adolescents: child and adolescent psychiatry, paediatric units; 14: cash benefits.

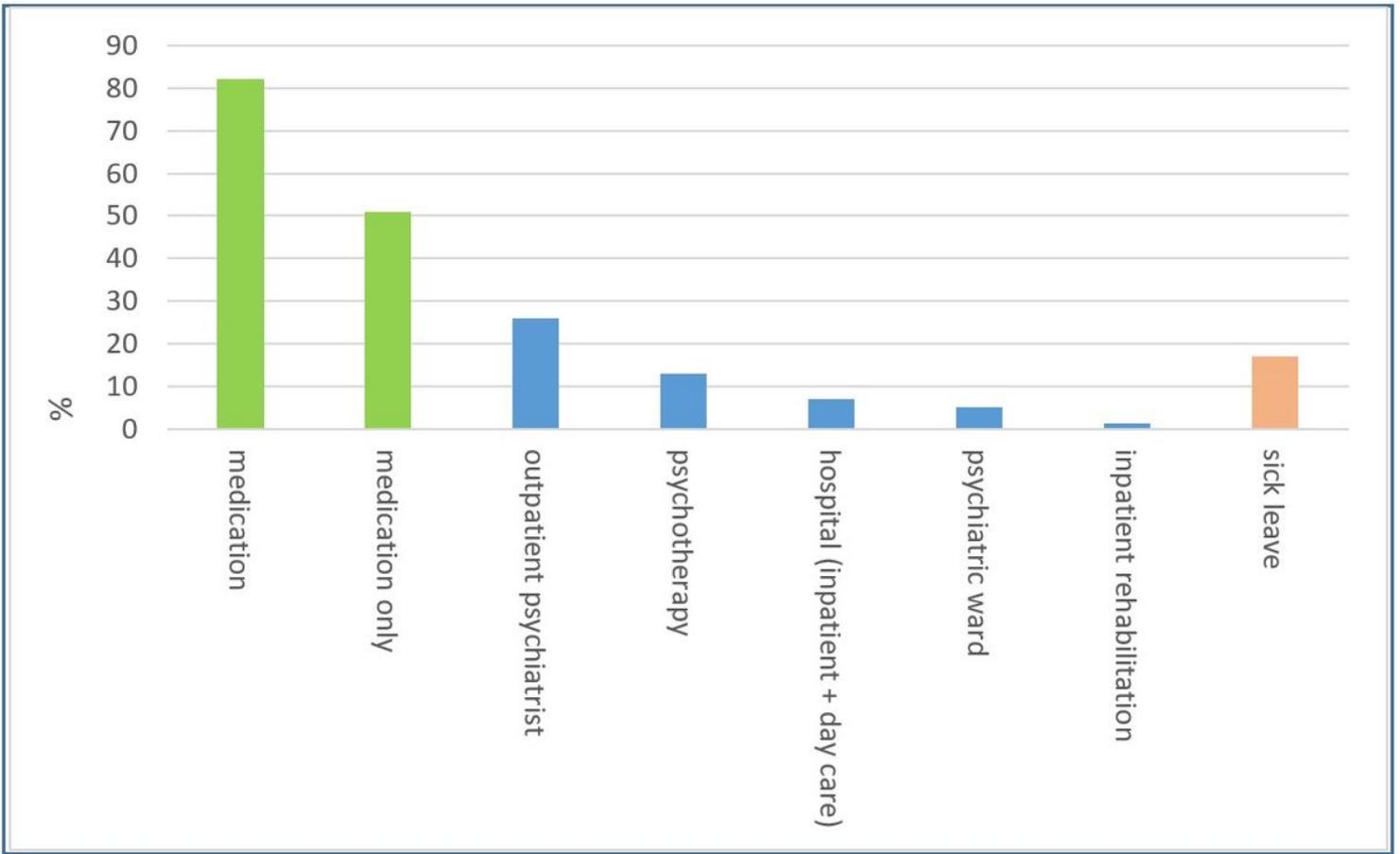


Figure 4

Use of benefits in 19-64 years old service users (n=49,494); 2017. Use of more than one benefit per patient possible.

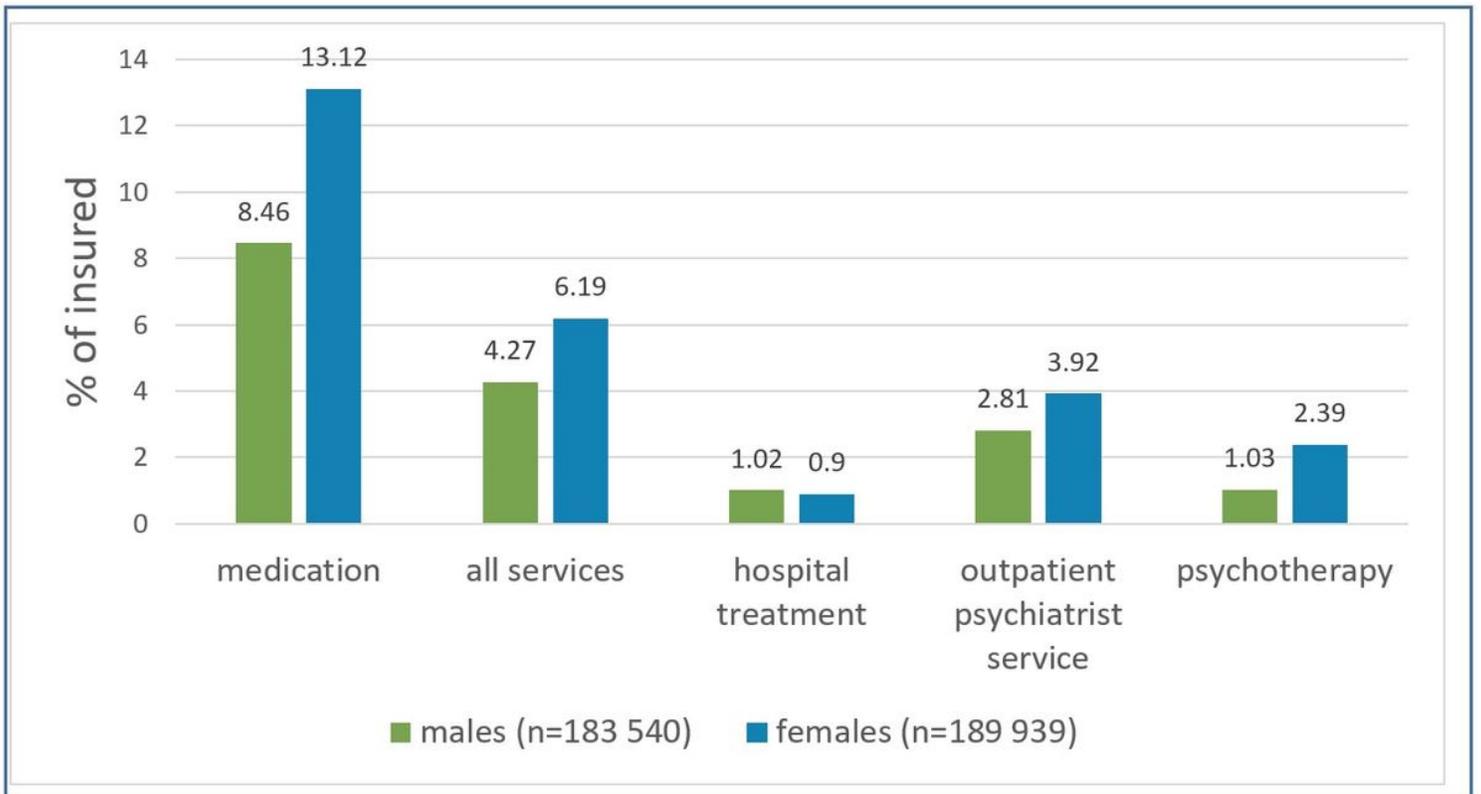


Figure 5

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Topicguide20180626ENfinal.docx](#)