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# Transitioning from Child to Adult Mental Health services: what role for Social Services? Insights from a European survey

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#### ABSTRACT

- 6 **Purpose**: Young people transitioning from child to adult mental health services are frequently also
- 7 known to social services, but the role of such services in this passage and their interplay with mental
- 8 health care system lacks evidence in the European panorama. This study aimed to gather information
- 9 on the characteristics and the involvement of social services supporting young people approaching
- 10 transition.
- 11 **Design**: A survey of 16 European Union countries was conducted: country respondents, representing
- social services' point of view, completed an ad hoc questionnaire. Information sought included details
- on social service availability and the characteristics of their interplay with mental health services.
- 14 **Findings**: Service availability ranges from a low of 3/100,000 social workers working with young
- people of transition age in Spain to a high 500/100,000 social workers in Poland, with heterogeneous
- involvement in youth healthcare. Community-based residential facilities and services for youth under
- 17 custodial measures were the most commonly type of social service involved. In 80% of the surveyed
- countries youth protection from abuse/neglect is overall regulated by national protocols or written
- 19 agreements between mental health and social services, with the exception of Czech Republic and
- 20 Greece, where poor or no protocols apply. Lack of connection between child and adult mental health
- services has been identified as the major obstacles to transition (93,8%), together with insufficient
- involvement of stakeholders throughout the process.
- Originality: This is the first survey gathering information on Social service provision at the time of
- 24 mental health services transition at a European level; its findings may help to inform services to offer
- a better coordinated social-health care for young people with mental health disorders.

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## **IMPLICATIONS:**

- 28 1. Marked heterogeneity across countries may suggest weaknesses in youth mental health policy
- 29 making at the European level,
- 30 2. Greater inclusion of relevant stakeholders is needed, to inform the development and
- 31 implementation of person-centered healthcare models
- 32 3. Disconnection between child and adult mental health services is widely recognized in the social
- 33 services arena as the major barrier faced by young service users in transition; this 'outside'
- 34 perspective provides further support for an urgent re-configuration of services and the need to address
- unaligned working practices and service cultures.

- **KEYWORDS**: social services, child and adolescent mental health services; youth mental health;
- 3 Europe; transition; surveys

## Introduction

Young people approaching adulthood face a number of personal and systemic changes. Those who are users of a number of services, whether education, health or social care, face a disjunction between child and adolescent-orientated and adult-orientated parts of the service. These transitions can also affect each other (Hovish *et al.*, 2012). Transition from Child and Adolescent to Adult Mental Health Services (respectively CAMHS and AMHS) in particular poses major challenges to young service users and their families. This daunting passage is often impeded by the existence of a great divide between mental health (MH) services (Singh *et al.*, 2010; Paul *et al.*, 2013), causing care discontinuity when young people (YP) need it most (Kessler *et al.*, 2007; McGorry *et al.*, 2013). Such a transition gap can lead to delayed mental health (MH) care (Copeland *et al.*, 2015), risking a worsening of clinical conditions with their burden (Gore *et al.*, 2011) and a possible increase of healthcare costs, yet to be calculated (Zechmeister *et al.*, 2008). From a societal perspective, this risk does not only affect individuals and their families, or healthcare system expenditures, its impact extends to associated public services, like social services.

Young people attending CAMHS or AMHS are frequently also (either on voluntary or compulsory basis) users of social services. This can be the case for looked after adolescents in foster care, young offenders, abused or psychologically traumatised children, or youth with complex needs (i.e. intellectual or motor disabilities or being children of parents suffering with mental illness). Scenarios can be manifold: some young people leaving CAMHS also will have received intervention from social care services and vice versa (DH *et al.*, 2015); others will have needs for social care and mental health care support respectively even though they were not in receipt of such intervention prior to the transition process starting. Youth with mental health difficulties have a higher rate of conduct and substance use disorders that continue into adulthood (Teplin *et al.*, 2002; Copeland *et al.*, 2007), which can bring them into contact with the police and social services (Constantine *et al.*, 2013). Furthermore, youth with social and family adversity, who are known to social services, are

more likely to be attending mental health services (Tarren-Sweeney 2008) and are at a greater risk of
falling through the MH care gap at the time of transition (Butterworth *et al.*, 2016). Leaving CAMHS
care and being discharged to the General Practitioner (GP) is as well a significant challenge at the
transition age (Sims-Schouten and Hayden, 2017) together with social and educational transitions
happening at this time (Glynn and Maycock, 2019), where, again, social services can be involved.
Indeed, for some young people 'aging out' from CAMHS transition from care itself can adversely

affect health and well-being (Dixon, 2008).

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Ongoing need for mental health care may well continue beyond usual health and social service transition boundaries, and needs to be carefully considered and planned for. Research has indicated the need to improve the experiences and outcomes of young people with mental health problems who leave child and adolescent mental health services (CAMHS), whether they meet the differing criteria for ongoing specialist mental health services for adults (AMHS) or not (DH et al., 2015). Research has also highlighted significant inadequacies in the management of MH services transition (Signorini et al., 2017 and 2018; Singh et al., 2017; Department of Health, 2014), in parallel with evidence and suggestions about what "good transitional care" should look like (Coleman et al 2004; Singh & Tuomainen, 2015). Additionally, whilst research into this area may be vast, systematic reviews have underlined the lack of clinical trials in this sector (Paul et al., 2015) and there is less evidence that policy has been developed in the majority of European countries to address this more formally. Despite this attention toward MH sector, it looks like in most EU countries social services have not received equal investigation (Coyle and Pinkerton, 2012; Holt and Kirwan 2011; Cashmore and Mendes, 2015). The aim of this paper is to present information on the characteristics of social services across the European Union pertaining to their involvement in supporting young people attending CAMHS as these young people approach and cross the upper age limit (transition boundary) of their CAMHS. As part of the BLINDED PROJECT NAME project, we extended the scrutiny of transition-related practices and approaches from MH services to include social care agencies. Details about BLINDED

1 PROJECT NAME have been published elsewhere (BLINDED NAME et al., 2017; BLINDED

**NAME** *et al.*, 2018).

## Definitions:

When we refer to 'transition' it is important to keep this term distinct from 'transfer', which represents only a discrete administrative event. Transition has more to do with "a co-ordinated, purposeful, planned and patient-centred process that ensures continuity of care, optimizes health, minimizes adverse events, and ensures that the young person attains his/her maximum potential. It starts with preparing a service user to leave a child-centred health care setting and ends when that person is received in, and properly engaged with, the adult provider" (Singh & Tuomainen, 2015). Transition outcomes includes different scenarios, i.e. accessing AMHS, being referred to GP, accessing other adult services meeting their care needs (i.e. people with Autism Spectrum Disorder do not access AMHS, but get support from other services, including social ones) and, unfortunately, also get lost in the service gap, disengaging from care.

In this paper, we have broadly defined **social services** as those public agencies operating the benefit/welfare of the community members "who have additional needs beyond what health, education or community services can help with. They also have a duty to safeguard children and vulnerable adults who may be at risk of harm, whether from family members or others. Levels of support can vary within each local authority and although the law defines what their duties are they also have their own 'thresholds' as to when they will provide a service" (Family Lives 2018). This is represented by, but not limited to, government founded organizations in the form of services like child safeguarding, education, food subsidies, health care, job training and subsidized housing, adoption, community management. Voluntary/charity agencies could also be included in this definition of social services and to be specified by survey participants.

#### **Materials and Methods**

Experts or actual representatives of social services, in each EU country were identified with
the help of BLINDED PROJECT NAME consortium principal investigators, and the survey was
addressed to one respondent per participating EU country. Affiliations of respondents are shown in
Appendix 1. Individuals were approached and invited to participate by email; if we did not obtain a
reply after three approaches, or if they declined, an alternative respondent was identified for that
country. Respondents were informed their replies would be considered as representing their entire
country situation and they were encouraged to seek information from other individual/agencies with
data about their social services provision.

A seven-item questionnaire was developed to collect the necessary data (Appendix 2) and sent to participants between March 2016 and February 2017; questions covered the following research questions:

- 1. Organization and delivery of social care for transition age youth; this includes:
  - social workers' distribution for YP under the transition boundary (TB) (Q3)
- type of social service involved in transition planning for YP with mental health problems under their TB (Q4)
  - types of benefits provided for YP under TB (Q5);

- 2. **interplay between mental health and social services**, meaning:
  - participation of social services in mental health service planning and development (Q2)
  - presence/absence of protocol or written agreements between mental health and social services in terms of child protection (Q6);
  - 3. **involvement of stakeholders**, in the formulation/implementation of social services policies, that is:
    - participation of carers'/service user associations for those with mental disorders in social service planning and development at national level (Q1);
- 4. identified **obstacles to transition** from social services point of view, meaning:

- express an opinion on what sorts of difficulties YP who need transitional care most often experience (Q7).

Questions were either multiple answer or single answer type, two of them required Likert scale ratings. Queries and requests for missing data were made via email, with up to three email reminders sent. Data were collated in Microsoft Excel 2013 (Microsoft Corporation, Redmond, WA, USA) and analyzed using descriptive statistics.

#### Results

9 We obtained information from 16/28 EU countries (see Table 1). More than 89% of survey 10 items were completed.

## Organization and delivery of social care for transition age youth

Details of the availability of social workforce were obtained for only 6/16 (37,5%) countries. The number of social workers per 100,000 YP who have not yet reached the transition boundary (i.e. aged under 16-21 years old) ranged from a low of 3/100,000 in Spain and 3,5/100,000 in Lithuania, to a high of 360/100,000 in Sweden and 500/100,000 in Poland.

A range of social care agencies is listed in Table 1. Each distinct service may be involved to a differing extent in the transition planning for YP with mental health problems. We therefore asked respondents to indicate which social care agencies are available in their country and to rate them on a 1 to 5 Likert scale, where 5 stands for full involvement in transition planning and 1 for no involvement (Table 1). Community-based residential facilities for children and YP, and services for YP under custodial measures or on probation, were most commonly involved (each scoring 2.9). Drug treatment services (2.7), general social services (2.6) and family counselling services (2.6) were also fairly often involved. Other forms of social services, such as ombudsman (2.0) and social street workers (1.8) were generally not involved. There was marked variation in overall scores across the countries, with Lithuania (32) and Spain (32) having the greatest reported involvement of various

social services in YP's mental health transition planning and Greece (5) having the least. Even countries with the highest scores had potential weaknesses though. In Spain, for example, despite high levels of involvement of social services generally, community-based residential facilities were not often involved in mental health transition planning. In some countries with a moderate overall score, Netherlands (16) and UK (20) for example, involvement of social care agencies seems sporadic, with many, at best, only sometimes involved in the transition planning (Table 1).

7 Table 1

The survey enquired as to whether YP with a mental disorder were offered any specific benefits at the time of transition, such financial help, institutional/healthcare support, ongoing educational opportunities, and support for parents and caregivers (Figure 1). Institutional as well as medical (including psychiatric) care was available in all the countries that responded (N=15). The majority of respondents also indicated that disability benefits (86.7%, 13/15 countries), specialized education programmes (80%, 12/15) and practical help for carers (80%,12/15) were routinely provided in their countries. Parental training/education was available in almost two thirds of the countries (73%, 11/15), whereas a buddy system was provided in less than half the countries (40%, 6/15). Other forms of benefits (delivered through charities or housing support) were also available in some countries (40%, 6/15). Respondents from two countries (Greece and UK) declared that no specific benefits were provided at the time of transition (although this depended on illness type and severity, not better detailed).

Figure 1

## Interplay between mental health and social services

In the last two years (i.e. 2014-2015 or 2015-2016), the involvement of social service professionals in MH planning has been reported to happen frequently in 31.3% (5/16) countries but rarely in 25% (4/16). Only in Belgium and Italy (12.5%) were joint policies between health and social services already in place.

National protocols or written agreements between mental health and social services on how to deal/act jointly in the case of child abuse/neglect were in place in all or most geographical areas in the majority of countries (12/15) and in many geographical areas within Belgium. Only Czech Republic, where child safeguarding instructions are only indicated in the general law text, and Greece lacked any such national protocols or written agreements.

## Involvement of stakeholders

The degree of participation of caregiver/service user associations in the planning and development of social services varied considerably across countries, with 62.5% of respondents (10/16) saying that these associations were not routinely or rarely involved in the formulation or implementation of social policies, plans or legislation at national level. In only a third of countries (5/16), was such consultation frequent.

#### Barriers to transition

In terms of obstacles hindering YP making a transition from CAMHS to AMHS and known to social services (Table 2), the survey respondents identified a number of common difficulties - 15/16 of countries (93.8%) reported a lack of connection between CAMHS and AMHS, 11/16 countries (68.6%) noted systemic cultural differences between services,10/16 countries (62.5%) identified a lack of specific competencies in AMHS and a similar number (62.5%, 10/16 countries) identified ignorance of other service systems.

**Table 2** 

## Discussion

# Organization and delivery of social care for transition age youth

The data gathered in this survey demonstrate a heterogeneity in social service provision at the time of CAMHS to AMHS transition between European countries. This mirrors the findings from a previous CAMHS mapping exercise carried out in all EU countries (Signorini *et al.*, 2017, 2018). For example, the numbers of employed social workers for young people does not seem to reflect country

size or population density (Rescorla et al., 2007). There seems to be a parallel heterogeneity with staffing levels in CAMHS when it comes to being in step with prevalence rates of child and adolescent mental disorders (Rescorla et al., 2007; Signorini et al., 2017).

Mean ratings indicate substantial concordance regarding the importance of social care agencies' involvement in mental health transition planning for YP in residential care, or with forensic or substance-related needs (i.e. Community-based residential facilities, services for YP under custodial measures or on probation, drug treatment services). This can be partially explained by the mandatory role of social services following juvenile Court decisions, but it also underlines the importance of social rehabilitation for YP with mental health difficulties. Despite such findings, the degree of such involvement does vary considerably between countries. Shelters for migrants and refugees, for instance, are an important aspect of support in Italy, Lithuania and Spain, whereas they seem to play a more marginal role in the other countries. This does not reflect, however, the extent of migration in Europe, which places these three countries at the 14<sup>th</sup>, 16<sup>th</sup> and 23<sup>rd</sup> place (Eurostat 2016), suggesting different sociocultural and political beliefs having influenced the development of services in each country.

Financial help for transitioning YP and their families appears to be provided through manifold channels: respondents of the CAMHS mapping survey (Signorini *et al.*, 2017) confirmed the presence of subsidies or free ancillary benefits from the government and substantial attention toward caregivers (in the form of practical help or parent training).

## Interplay between mental health and social services

Great variability is also observed in the way social services interface and jointly work with the health care system when supporting YP transitioning form CAMHS to AMHS.

Great variability is also observed in the way social services interface and work jointly with health services when supporting young people transitioning from CAMHS to AMHS. For example, while around one third of surveyed countries indicated that social services were regularly involved in MH planning, only two countries reported that joint policies between health and social services were

in place. This calls for the implementation of more structured joint activities under a shared management framework (Vloet *et al.*, 2011). In addition, if one considers that the process of a young person 'leaving care', that is, the point at which a young person is no longer legally looked after by social services, can also coincide with their mental health transition, it may be reasonable to think that both services may benefit of joint protocols, as both processes tend to occur in the 16-18 age range of their users in common. This may facilitate and optimize the efforts made by both services to identify and address ongoing needs for YP reaching the upper age boundary of child-adolescent care.

In concordance with previously reported findings (Signorini *et al.*, 2017) regarding child-safeguarding policies, referral of severe cases of neglect or abuse is regulated by specific referral protocols in the majority of surveyed countries. There are still, however, European countries where inter-service communication and sharing of such important information does not happen regularly or consistently, nor appear to be mandatory. This represents a significant challenge in the development and implementation of even more specific youth policies. If basic safeguarding is not guaranteed, how can additional initiatives for your wellbeing be reasonably implemented?

## Involvement of stakeholders

The involvement of service user/family associations in social service planning at national level is also uneven; they are routinely consulted (meaning invited to meetings for the formulation/implementation of the policy/plan /legislation) only in one third of the countries. This represents an important criticism for an adequate person-centered care delivery system in general (Blum *et al.*, 2012), not only for transitional care. We cannot exclude stakeholders' associations may happen to be engaged informally at local level, even when not advised or mandated in policy, although this scenario can be hardly mapped and we can speculate substantial heterogeneity applies form a local reality to another.

#### Barriers to transition

Previous research concerning the transition of youth with MH problems (Signorini *et al.*, 2018) has identified a critical gap between CAMHS and AMHS, a feature which was also evident in

this survey. The overwhelming majority of the respondents representing social services viewed the disconnect between CAMHS and AMHS as a barrier to successful transitions experienced by YP in their countries. Furthermore, cultural differences between the services (i.e. protection vs autonomy oriented approaches) were also seen as a barrier, followed by the lack of specific competencies among staff in AMHS (i.e. lack of training on neurodevelopmental disorders). This is probably in line with a more 'social reading' of the phenomenon and its complexity in terms of cultural approaches and services interplay at the community level. Contrary to expectations, AMHS caseload was viewed as a barrier in a smaller number of countries.

#### Limitations

Caution should be adopted, when interpreting these data, as a considerable proportion of it is based on respondents' personal opinion, in many cases belonging to the healthcare sector, rather than official national registries or sources. This represents an important methodological weakness.

A lack of standard definitions for many concepts used or rated in the survey may have as well contributed to the variability in responses as no glossary of terms was included. Different interpretations of terms used in this tool may therefore account for some of the country differences, together with the heterogeneity of experts' reference systems.

In addition, whilst this paper does not report the views of young people or their carers, the BLINDED Project within which this survey sits has a number of complementary aspects, including significant PPI (Patient and Public Involvement) as evidenced by number of outputs (Street *et al.*, 2018; Wilson *et al.*, 2015)

## Implications for policy and future research

Country variability in social service provision and their involvement in MH may reflect national architecture and policies regulating joint responsibilities across services, as well as service user characteristics, not captured by this survey. Alternatively, the lack of uniformity across EU countries in the way YP are supported during mental health service transitions, and the lack of

involvement of key stakeholders in service planning, may signal a pressing need to set adequate international quality standards and quality assessments.

Future research initiatives in this field may overcome some methodological limitations present in this study by i) including representatives of social services identified through more structured/official pathways (social services national/international associations), ii) extending the survey to services users and they families, iii) providing a more rigorous definition of key terminology, iv) including social service experts while developing survey questions. Results presented here can guide future investigations throughout Europe or internationally, to explore country heterogeneity in more details, as well as to research focused, on key target subgroups of the youth population, (e.g. looked after children with ongoing MH needs, YP affected my mental disorders and in juvenile justice services, etc...)

In terms of practical implications, results here presented can inform both MH and social services managers about the need of joint protocols for young users aging out from their services. This can be started at local levels and progressively tested to be implemented regionally and nationally. Co-ordinated multi-agency working is widely recognised as invaluable in supporting children and young people (Sidebotham *et al.*, 2016; DH *et al.*, 2015) and, in some countries, there are already legal or national policy instruments in place that could form the basis for systematically developing collaborative working across mental health and social services. In the UK for example, Education, health and care plans (EHCs) are legal documents that outline the support a young person up to the age of 25 should receive. There are also NICE guidelines and a quality standard applicable to both health and social care for young people in transition from children's to adults' services (NICE 2016). These guidelines have important recommendations on how to improve transition in mental health care and what can be the markers of optimal transition (Singh *et al.*, 2008) - that are good i) information transfer; ii) a period of parallel care in CAMHS and AMHS; iii) planning; iv) involvement of the young person by one meeting with professionals for both services. Social services might play a role by facilitating the transfer of information to AMHS for those cases they keep under

they care after YP leave CAMHS, as well as adopting the parallel care (ii) and joint meeting (iv)
suggestions when their young services users both reach MH service transition boundary and age out
of social care. National policies may develop afterwards, but starting up-front implementing these
suggestions and collecting effectiveness and efficacy data on local initiatives may better inform

policymakers and the community on what can be already improved.

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#### **Conclusions**

This study gathered information on the characteristics and the involvement of social services supporting YP crossing their mental health care transition boundary. Differences between countries are to be expected, but such marked heterogeneity may suggest weaknesses in youth mental health policy making at the European level and a failure to learn from practice and policy as to 'what work. Despite a significant growth in tools for measuring young people's health and wellbeing outcomes and the development of electronic avenues for collecting and promptly sharing these data, sadly implementation remains highly variable; standardized assessments of service practice as well as shared outcome measures are strongly recommended to improve the quality and consistency of YP transitions in all EU countries, in both social and health care services. Even if financially supported, YP and their families are often excluded from critical discussions when health and social care policies are developed, underlining the urgent need for the prevailing practices to be overhauled to allow a more person-centered model of care. The disconnect between CAMHS and AMHS is the major barrier identified along the transition journey, according to experts from both mental health and social services. Despite a raft of initiatives over the last decade to address this service chasm, (e.g., joint training, the creation of new multi-agency planning and commissioning forums and of posts shared between children's and adults' services), problems persist. It is therefore imperative that going forwards, policy and practice initatives must ensure that not only are all relevant stakeholders fully involved, if we are to drive the implementation of appropriate evidence-based transition support, but that this is undeprinned by propert resourcing and clarity about lines of responsibility.

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