Seminar on "Moving towards independent living and community-based care - EU funding instruments to support the development of community-based services for children without adequate parental care"

Practices Fiche – Austria

Helping Children find the Support they need: Mental Health Village Project in Tyrol

Zagreb, Croatia, 14 March 2019
DG Employment, Social Affairs and Inclusion

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Seminar on "Children without adequate parental care moving towards life in the community"

DG Employment, Social Affairs and Inclusion
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# 1 Introduction

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<thead>
<tr>
<th>Full name of the project:</th>
<th>Das Village Projekt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsible organisation for implementation:</td>
<td>Dr. Jean Paul, PhD, BASc, BSc (Hons) Ludwig Boltzmann Gesellschaft, Wien Medizinischen Universität Innsbruck</td>
</tr>
<tr>
<td>Geographical scope:</td>
<td>Western Austria (Innsbruck, Tyrol) implemented by an international research team (Australia, Germany, Norway, Pakistan)</td>
</tr>
<tr>
<td>Total duration of the project:</td>
<td>4 years</td>
</tr>
<tr>
<td>Time frame (from mm/yy to mm/yy):</td>
<td>04/18 to 04/22</td>
</tr>
<tr>
<td>Beneficiaries/target group:</td>
<td>Children of parents with a mental illness (COPMI) aged 0-18</td>
</tr>
<tr>
<td>Type of service/support/measure (specialised, mainstream):</td>
<td>Specialised: mental illness, disability; Multilevel: international, national and regional; Multi-resources: service planning, health reports, legal documents, children books, testimonials and documents; Multi-approach: healthcare, social affairs (including informal care), education, criminal justice.</td>
</tr>
<tr>
<td>Area of activity (e.g. housing, social service, employment, transport, healthcare etc.):</td>
<td>Relevant welfare system services and stakeholders (multidisciplinary approach).</td>
</tr>
<tr>
<td>Total amount of funding:</td>
<td>EUR 3 million</td>
</tr>
<tr>
<td>Source of funding (EU/national, if EU, under which EU funding programme):</td>
<td>National</td>
</tr>
</tbody>
</table>

## 2 Scope and main objectives of the project

The Research Project ‘Village’ aims to identify and support children of parents with a mental illness (COPMI\(^1\)) in the Tyrolean region of Austria and helps breaking the cycle of intergenerational transfer of childhood adverse experiences. These children, usually referenced as COPMI in literature, are less likely to be included in national or regional statistics until accessing treatment. Researchers state that ‘as a result, they remain invisible and their needs may be unmet.’ (Paul, 2018).

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\(^1\) Children of parents with a mental illness will be referenced as COPMI through the document.
The project can be summarised in four main objectives:

1. Firstly, the project started with an evidence-based analysis to help identifying the target group. Therefore, a mapping of existing structures and services in Tyrol was performed through a selection of relevant actors and sectors (healthcare, social care, education and informal networks).
2. Secondly, the project tries to select the most relevant approaches for child support through interviews with local stakeholders and facilitated workshops.
3. The third scaled objective is to develop interventions, trainings, tools and child-focused support networks based on ‘child’s voice’ and on collaborative practices.
4. Lastly, an impact evaluation with a global cost estimation and scalability opportunities in other regions and at international level is carried out.

The project is run by Dr Jean Paul from Murdoch Children’s Research Institute in Melbourne now based in Innsbruck. She coordinates a multidisciplinary team of seven researchers from six different countries.

3 Main activities of the project

The very first step of the project was the creation of a management structure, headed by a steering committee. This operational management team coordinates an advisory board of people with lived-experience and experts. The competence group, which consists of 6 children belonging to the target group (COPMI), reports to the researchers’ team and jointly reports to the advisory board together with an investigator’s team.

In 2018, a research team started to review international research and published their report focused on the Tyrolean context. Two project reports are available on the Village website: the first describes mental health services by mapping existing support and structures (Zechmeister-Koss and Goodyear, 2018); the second is an analysis of the prevalence of mental disorders and uptake of mental services (Zechmeister-Koss and Tüchler, 2018). Both papers specifically cover the region of Tyrol. Statistical findings are based on data from the Tyrolean health insurance provider covering the last 6 years (from 2012 until 2017).

From April 2018 until June 2018, interviews and focus groups were conducted with mental health professionals from services for adults, children and adolescents to co-design interventions, helping with the screening of the target group of children. These stakeholders were also asked if they wanted to take a role as village facilitators in the project. This role endorsed by professionals among Mental Health services for adults, children and adolescents, combines two main tasks: coordinating support for children and taking part in the evaluation of interventions.

From October 2018 until March 2019, experts with lived experience and stakeholders previously identified through research and interviews have been meeting during 6 monthly workshops. The aim of these workshops is to complement evidence-based research, co-develop support interventions and identify possible central pitfalls in the implementation.

From September 2019 until September 2020, professionals, community members and Village facilitators will be trained and will receive mentoring support to sustain COPMI. To this end, 3 workshops of 2 hours each and monthly mentoring will be implemented.

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2 i.e. Students and PhD students who can also be internationally based.
3 Lasting 1 or 2 hours
4 2 or 3 hours
5 Parents, children, health care professionals, youth services, school supporting staff, NGO’s.
6 of 2 till 3 hours each.
Training experts also help services with implementing a change process (including ‘COPMI-friendly practices and support’).

The project last year (i.e. 2021-2022) will be dedicated to measuring the impact of interventions with all project stakeholders, through interviews and surveys.

4  Stakeholder involvement in the design and implementation of the project

The project puts great emphasis on families’ participation aside professionals from healthcare, social care and educational sectors. Noticeably, the Competence Group, meeting with the researchers once a month is composed of 6 children (COPMI). People with lived-experience are part of the management board and all stakeholders are part of the evaluation process. During workshops, participants (children, professionals and community members) are encouraged to give feedback on the implementation. Child participation is at the centre of the methods used in the project implementation. Some examples include co-participation with children through roundtable discussions or child-friendly data collection to understand and conceptualise the child perspective and experiences. Additionally, there is a specific Work Package (WP) dedicated to the child’s voice and to the ways through which children wish to participate in discussions about their own needs. Findings of this WP will be implemented throughout further adult trainings. The project is also centred on the UN Convention on the Rights of the Child (UN CRC) principle of acknowledging the ethical imperative and rights for children to be provided with their own health information, as defined on the Village website.

The Village project outline meets the nine basic requirements for effective and ethical participation provided by the Council of Europe (Council of Europe, 2016), from transparency in each implementation phase until involvement in final evaluation.

5  Main results and impact to date

Although the Village project is not a typical deinstitutionalization project (i.e. project that results in the closing of a specific institutional setting), its value lies in the identification of invisible children at risk of out of home placement and the support of the community around them.

The two project reports provide learning on how alternative guidelines on gatekeeping of looked after children are respected, how prevention networks are organised to avoid out-of-home placement and how the project research and outcomes help identify and then support children and families, where mental health is an issue.

Mental health problems at parental level have been identified as a key reason for out of home care for children: According to the latest child and youth welfare statistics, 6.5 per 1 000 children below 18 years received full parenting outside home in 2016 in Tyrol. The rate was lower than the Austrian average (9/1 000). In an earlier report, reasons for living outside home were analysed by one large provider. In the Tyrolean region, deinstitutionalisation processes have occurred and the mapping report further states that primary healthcare, psycho-social provisions in the community, outpatient services

7 https://www.village.lbg.ac.at/about
9 ‘All types of hospitals together provide 5 004 beds representing 677 beds per 100 000 inhabitants (Austrian average: 749/100,000) [23].’ (Zechmeister-Koss and Goodyear, 2018). In 2011, 960 000 patients relating to 2 million cases were treated in hospital outpatient clinics in Tyrol. The frequencies of hospital outpatient hospital services were highest in Tyrol compared to all other Austrian regions. (Zechmeister-Koss and Goodyear, 2018).
have increased and self-help groups recognition is enhanced as well. However, the report highlights two planning and coordination problems: a lack of regular mental health reporting in Tyrol and a lack of consistency in the geographical spread of those services and benefits.

Furthermore, the mapping report of existing Tyrolean support and societal structures helps identifying mental health detection problems and therefore mentions other relevant actors in the detection process: referrals from hospitals, outpatient psychological or psychiatric services and midwives are more frequent than from social workers, social services or paediatricians. Self-referrals are rare and in 1/3 of supported families, mental health problems were detected at a later stage, only during the support phase. The research showing a trend in referrals restricted only to some professionals, could be explained by the fact that there is a limited amount of adolescent outpatient psychiatrists and psychologists with a public health insurance contract and other professionals can only be accessed with a private insurance coverage.

The report questions the lack of a defined mainstream ‘first point of service’ for children of parents with a mental illness. Keeping detection problems in mind, the Village project aimed at finding several entries to bridge knowledge and statistical gaps. The research has calculated approximations or identified statistics that are cautiously presented as underestimates. The Village researchers estimate that there are 27,000 children aged below 15 who live with a parent with a mental illness. The report also mentions an approximation of 6,000 young carers in Austria.

Although research could not identify the total number of children in need in Tyrol, it could streamline different channels for their identification and, therefore, selected support methods are also diverse. I.e.: some parents and children receive information other families receive information package and additional help for the children.

6 Main challenges and success factors

Researchers of the Village project have identified the lack of data as a first challenge. Based on Tyrolean healthcare insurance data, there is no way to get completely accurate statistics about the target group of the project. Researchers work with approximations and international percentages and hypotheses to get best possible estimates.

Legal issues around privacy can also be a barrier in terms of data sharing and coordination. Nevertheless, researchers of the Village project suggest it would be more efficient to coordinate existing services recognising their potential at improving support of COPMIs in Tyrol instead of creating completely new ones.

The researchers highlight that governance in the healthcare sector is divided upon many levels. For example, hospital care is financed by the health insurance, the regional government and the federal government, while legal responsibility for providing capacities and personnel rests within the regional Tyrolean government (Zechmeister-Koss and Goodyear, 2018). Access to benefits, whether in cash or in kind, can be restricted through the type service provision (public and private providers), gatekeeping (referral from youth services as a pre-requirement for support) or capacities shortage.

The report has identified that certain actors of the welfare system11 are beneficial for the identification and support of COPMIs.

10 ‘According to Tyrolean demographic data, 108 000 children below the age of 15 live in families in Tyrol. Data for the age group 16 to 19 years have not been presented in the statistics. International figures have shown that 25% of children are living with a parent with mental illness worldwide [1-5]. This would equal 27,000 children < 15 years in Tyrol.’ (Zechmeister-Koss and Tüchler, 2018).

11 Ranging from educational support actors to informal help groups
The cross sector and level organisation needed will probably require more financial involvement, according to the researchers.

The Village website is full of resources and valuable descriptive information. However, in order to find tools and practical outcomes, visitors have to check media coverage or secondary communication. This information could be up-levelled on the main page.

Many intersectionality issues were covered through the research. Children in rural zones getting less support options, single parenting, all services and benefits users are analysed through a gender lens. For instance, medications on prescription are proportionally higher for male patients before 19 and rise for female patients after 19 years old.

The website documents different steps of the project through implementation, workshop invitations and main goals. There is a forum on the website and the Village Project organisation is also visible on social media.

The project combines different approaches to identify and support children of parents with mental illness qualitatively and quantitatively. All outcomes are accompanied by useful knowledge on type of beneficiaries, (in- outpatients, children and or parents) and specific context (education, healthcare, social care or even criminal justice). Last year, a practical example of a tool on social competences was presented to the media: an online game designed in co-production with the Karl Landsteiner private university in Krems. Children are encouraged to remain in contact with their school friends during the transitioning phase from elementary school to higher education levels. ‘The tool encourages social competences and online contacts but also in real life through child-oriented tasks.’ (Meergraaf M., 2018)

The expected outcomes of the project by 2022 will be communicated at a conference and include the amount of professionals trained, tools developed, co-designed projects, number of parents and children identified, disseminated information based on research, stakeholder satisfaction and cost efficiency. As the project is still being implemented and collaborative input is welcomed at all stages through the ‘get involved’ tab of the Village Project website12.

7 Recommendations for sustainability and potential transferability of the good practice

In the Village Project, early intervention programmes for younger children are mentioned as referral whereas other services (mainly part of children welfare) provide support. As mental health prevention and support require a collaborative approach throughout the whole system, it might be interesting to compare the collaborative work of those services working with young children, their successes and limitations on COPMI related issues. International research could highlight additional best practices of smooth detection and support for younger children. For more advanced age groups, countries like the Netherlands have provided online tools for young carers. Self-detection is encouraged via online surveys13 or awareness campaigns. It might be useful to create an online tool for Tyrol that helps self-detection and introduces support options. These online tools could also dedicate a space or module or set of survey questions for COPMIs.

The Village research plans on including linguistic microanalysis of interactions and child-friendly data collection to understand and conceptualise the child perspective and experiences. There might be an opportunity to increase mental health literacy and address what other researchers have identified as the current ‘limited knowledge about of what kind of content should be delivered to children.’ (Riebschleger J., Grové C.,

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12 https://www.village.lbg.ac.at/getinvolved
13 https://2becool.nl/jonge-mantelzorger/doe-de-test/ 2 be cool is an organization for young carers coordinated by a regional organization (Palet Welzijn) that supports carers of all ages in the Netherlands.
Cavanaugh D., Costello S., 2017) The project would not only help support children, but also help enhance the information and tools on mental health literacy per age groups. Among practical outcomes and resources, the Village project could also advise on age-friendly recommendations on mental health.
## Annexes

### Check-list for identifying promising practices:

<table>
<thead>
<tr>
<th>Transitioning from institutional to community-based care</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Is it guaranteed that, as a result of the project, individuals are not just moved to smaller institutions, but are supported in community-based settings?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2: Did the project cover all service users/residents in the original institutional setting, or did it target only a specific group of service users?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3: Did the institutional care setting close down as a result of the project, or did it continue to operate on a smaller scale?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Compliance with human rights</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Was the project in line with the relevant provisions of the UN CRPD, UN CRC, EU Charter of Fundamental Rights and other relevant international human rights documents?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Involvement of different actors</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Was the project developed in an inclusive way (with the involvement of different stakeholders, including civil society organisations)?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2: Was the project implemented in an inclusive way (with the involvement of different stakeholders, including civil society organisations)?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3: Were services users and the representative organisations of the relevant target group (persons with disabilities, homeless people, children, users and survivors of psychiatry etc.) involved in the project design and implementation, through co-production?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supporting individuals and communities during transition</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
</table>
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<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Did a human rights-based individual needs assessment take place to ensure that the needs of all individuals are met during the transition?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>2: Were individuals prepared adequately to the transition through trainings and other measures prior to and after moving out of institutional care?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>3: Was the local community adequately prepared through awareness raising to welcome people leaving institutional care in the community?</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

**Impact on mainstream service provision**

<table>
<thead>
<tr>
<th>Question</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Do the individuals who benefitted from the project have now access to mainstream services and facilities (e.g. social housing, education, employment, health care, transport, sports and cultural facilities, childcare facilities and any other services from which the community benefits)?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sustainability of the good practice**

<table>
<thead>
<tr>
<th>Question</th>
<th>Very much</th>
<th>To some limited extent</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Is there any follow-up/quality assurance in place to ensure the smooth operation of the newly created community-based care services?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2: Is the support that individuals receive regularly monitored to ensure high quality?</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8 List of references:


