

# Supporting children with mentally ill parents in Austria: The ‘village’ project

## Summary

*Zechmeister-Koss I, Basli S, Bauer A, Christiansen H, Glatz-Grugger M, Goodyear M, Gruber N, Hölzle L, Schamschula M, Schöch P, Paul J*



### Where did we start from?

When a mother or father becomes mentally ill, this can be a particular challenge for their children regardless of age. We know from the international literature on stigmatisation that children can be worried about being teased because of their parent's illness and they may feel inferior or guilty about the illness. Many take on responsibility for parental tasks that are not age-appropriate (e.g. paying bills, cooking for themselves and others, caring for younger siblings) or even care directly for their parents (e.g. taking care of their medication). The fact that many of these children need emotional and practical support is often realised far too late. This is also due to the fact that the topic of "parenthood and mental illness" is often taboo, both among parents and professionals, partly because the parents are afraid of losing custody of their children.

This is not about individual cases. There are many adults who suffer from mental illness, e.g. depression or anxiety disorders. In figures, this means for Austria: almost a quarter of the adults up to 65 years of age surveyed were affected within one year. Therefore, there are many children who grow up with a mentally ill parent for a short time or for several years. Internationally, one in four children is estimated to be affected.

Some children can cope well with the situation. However, the consequences for who are struggling can be considerable: they often become mentally or physically ill themselves, can have difficulties at school due to the stressful situation and, as a result, suffer significant disadvantages later in life. For example, they are more affected by unemployment than children of mentally healthy parents, need psychiatric or other medical treatment or are more likely to be dependent on social benefits. In addition to individual suffering, this also has a considerable economic impact.

Targeted preventive services for affected families are rare and still little researched. In Tyrol, which was the focus of our analysis, we have identified a large number of services for the treatment of mentally ill parents and children in a detailed situational analysis, but no comprehensive preventive structures have been established to systematically identify and support children of all age groups before they become problems. The services for parents and children are in different areas of responsibility (e.g. social insurance vs. the province of Tyrol) and there is a lack of coordination by a responsible specialist, which is oriented towards the individual needs of the family. Because the capacities of publicly financed services, such as



psychotherapy financed by the health insurance system, are too low, the use of these services is often associated with private costs or long waiting times. In some situations, such as when a single parent has to be admitted to hospital for an acute mental crisis, there are gaps in care because there are no childcare facilities. Sometimes healthy children even have to be admitted to hospital for lack of alternatives. Another complicating factor is that for the majority of family-oriented services, such as those of child and youth welfare, there are access requirements. They focus on risks (e.g. for child welfare risks) and are primarily intended for families where there are already acute problems.

Professionals report that they need more knowledge about sensitive communication with parents and children and about available support services. The analysis also revealed that there is a high degree of social stigmatisation in Tyrol. In this context, this means that role models, especially the role of the mother, are sometimes strongly influenced by politically conservative and religious traditions. If mothers have mental health problems, prejudices about mental illness put these women under particular pressure. The professionals interviewed unanimously see a clear need for action to improve the situation in Tyrol.

There are several countries worldwide where preventive programmes are available, e.g. the "Let's Talk" programme in Finland. These are family-oriented offers, which consider people with mental illness in the context of their family relationships and take into account the needs of all family members. Research shows that the negative consequences for children can be reduced and parents can also benefit, even if the effects are often small. For example, children from the participating families were less likely to suffer from the same mental illness as the parent and referrals to child and youth services decreased.

With the "Village Project", the Ludwig Boltzmann Society and the Medical University of Innsbruck financed a three-million-euro research project to analyse in detail and subsequently improve the situation for affected children in Tyrol. Based on the African proverb "It takes a village to raise a child", it was guided by the idea of supporting and relieving the children in everyday life with the help of the family's social network. We drew on knowledge from international studies that have shown that social support can be a protective factor for mental health. The project was funded on the premise of connecting researchers with the public and involving stakeholders throughout the process ("Open Innovation in Science").

### **Improving the situation in Tyrol with the Village concept**

Our project goal was to co-develop, implement and evaluate an identification and support programme for affected families. It was important for us to take into account both international evidence and the Tyrolean initial situation, such as concrete gaps in care. The participatory development of the Village concept in the form of a research-practice partnership was a central component of the project. It made it possible to involve different relevant organisations and professional groups and, above all, to include the perspective of people with lived experience.



The participation process should enable the development of a programme that is relevant and sustainable for Tyrolean needs.

Across six workshops, representatives from 14 Tyrolean organisations from the health, social and educational sectors, as well as two adults with lived experience, developed a programme concept together with the research team. The participants assessed this participation process as predominantly positive. In addition, a group of young adults who grew up with mentally ill parents gave regular feedback on the results of the workshops.

The concept developed is to discuss with patients who are being treated for a mental illness whether they have children and how they and the children are coping with the situation (screening). A short, standardised questionnaire serves as a support. The approach of reaching the children through the treated parents was supported by social insurance data from 2017, which showed that about 50,000 adults up to 64 years of age used psychiatric/psychotherapeutic services financed by the regional health insurance in Tyrol. If the screening interview reveals that patients have underage children, they are offered the opportunity to participate in a support programme as a family free of charge. They are contacted by so-called village coordinators who accompany them in the programme.

In the course of the support programme, the coordinators discuss the everyday situation and support needs with the parents and children in a process lasting several months. They identify important reference persons for the children (e.g. relatives) and persons from the parents' social network (e.g. neighbours). This information forms the basis for an accompanied family meeting and a subsequent so-called network meeting, aiming to strengthen the network around the child. The parents, children and invited persons from their social environment consider, facilitated by the coordinator, who could help when crisis situations arise, or who can provide regular support in order to avoid future overburdening. A few weeks later, a reflection takes place and, if necessary, the agreements are adjusted. Due to Covid 19, an online version was developed for individual components of the programme.

It is essential that the children can actively contribute their views throughout the programme. This is supported by age-appropriate playful elements. For example, the children visualise the most important reference persons with figures in a spider's web. Another central aspect of the programme is that the Village coordinators adopt a cooperative attitude towards the families, which is oriented towards the strengths of the family and recognises the families as experts in their situation. The aim is for them to take more control of their lives (empowerment) and for the social network to organise itself in the medium term. The criteria for participation were that at least one child of the families is between four and 18 years old, sufficient German language skills and the affected parent's understanding of the illness.

### **Results from the pilot study**

Six psychiatric hospital departments and ten general practitioners, primarily from urban areas, took part in the screening and referral process after receiving training. For the follow-up of the



families, 12 coordinators trained for the programme were available. A total of 96 families were referred, 30 of whom completed the programme and participated in a final survey.

As part of the evaluation, interviews were conducted with the professionals, parents and children involved. Participants were interviewed before the programme began and after it ended. We applied quantitative and qualitative methods. The evaluation was based on a logic model which shows the connections between the programme components and expected changes. This includes, for example, better knowledge about mental illness and available support services, improvement in health status or quality of life.

The data collected before the start of the programme indicate a considerable burden on the children and parents surveyed. This concerns, for example, their state of health, stigmatisation in everyday life and excessive responsibility of underage children in the household.

Data after the end of the programme showed improvements in children and parents in terms of health status, knowledge about mental illness and communication about it within and outside the family, in the parent-child relationship and in the parent's willingness to accept support. The extent of stigmatisation and the assessment of quality of life, however, hardly changed. Satisfaction with the programme was very high among parents, while children gave mixed satisfaction ratings. In particular, families highlighted that the strengths based community support model was different to any other program that has been offered to them previously.

The complete programme, which according to the coordinators' records lasted an average of eight months and a maximum of 15 months, required on average around 40 working hours per family. This corresponded to costs of about € 1,130 per family or € 630 per child, which were covered by the project budget. In addition, overhead costs (e.g. quality assurance) have to be taken into account. The work of the coordinators with the families took place at different locations, often at the families' homes. The network meetings to support the families were usually attended by a maximum of four people in addition to the parent concerned and their children, most often volunteers, professional helpers (e.g. social workers) and family members.

According to the professionals involved, both the screening and the support concept are feasible but require support in their respective work environments, e.g. in the form of supervision. The biggest hurdle they mentioned was the willingness of the parents to talk about parenthood and mental illness and to motivate them to take part in the programme. During the programme, the professionals described the most challenging part as dealing with resistance from individual family members to the network meeting, particularly in inviting informal persons to the situation of the family.

Going beyond a traditional research project, the research team implemented accompanying measures to raise awareness of the topic, e.g. through contributions in (social) media. This was intended to counteract the high degree of stigmatisation found at the societal level.



## Discussion and conclusion

Our findings indicate that the Village Programme brought about positive developments in the participating families. For individual parents and children, the changes, even if minimal, had a great meaning. The concept has the potential to positively influence the mental health of both, starting with communication and family relationships, and ending with knowledge about mental illness. Unwanted consequences (e.g. relationship breakdowns with friends), on the other hand, were hardly reported. A limiting factor is that this is a feasibility study. In this type of pilot study, there is no comparison group and a small number of participants. Therefore, we cannot draw any definite conclusions about the effectiveness, but we do see positive trends.

Although feasible in principle, there is room for improvement, for example in the number of referrals and the participation rate. During the piloting, the facilitators had some flexibility in the delivery of individual program components, especially in framing the delivery of the network meeting. Not all elements of the programme could be implemented 1:1 as envisaged in the original concept. Above all, more time and contact with the families was needed to build trust and to have open conversations about the mental illness. A major reason for deviations was also Co-vid-19 and the associated contact restrictions.

Compared to the costs of psychiatric treatment for children when prevention is missed, the costs of the programme are extremely low. However, further studies comparing the costs and benefits of our programme with alternatives are needed for a robust economic evaluation. A sustainable financing of the programme has not yet been achieved. This is largely due to the Austrian financing structures and the silo interests of the individual funding agencies. There are hardly any funding possibilities for preventive, intersectional services, such as the Village Programme, which do not correspond to traditional therapeutic approaches. However, individual social organisations in and outside Tyrol have expressed interest in including the programme in their portfolio or offering staff training on the topic. In the future, it should be taken into account that families who were excluded from the pilot project due to resource constraints, such as those with little knowledge of German, can access the programme. A research-based further development of the programme is desirable.

It is without question that after the end of the project there is ongoing need for action to care for children and their families. We conclude this from the data on the current burden of the children, the existing gaps in care and the need to prevent long-term - especially economic - consequences. This requires intersectoral cooperation and it is necessary that prevention is given the political priority that has long been recommended internationally (e.g. by the WHO).

The need for further research on the topic is also evident. This relates, firstly, to the Village programme itself. More robust data on effectiveness and efficiency are needed, as well as knowledge on how to increase the referral and participation rates, especially of currently underrepresented groups (e.g. fathers). However, the need for research goes beyond the Village programme and concerns, for example, better care for mentally ill mothers and fathers with

small children under 4 years of age. In order to deal with such questions in a well-founded way, a sustainable research infrastructure for inter- and transdisciplinary mental health services research is needed, which goes beyond traditional clinical research at university hospitals.

Apart from the insights for the care of affected families, this research project has made a valuable contribution to international research, e.g. in the form of numerous publications and presentations. Research-practice partnerships bring challenges such as increased time requirements, but enable the development of regional solutions. This increases the chances that research-guided care concepts will also be implemented in practice.





# E-Mail-Contacts

Village



## Principal investigator

**Jean Paul**

Ludwig Boltzmann Gesellschaft Forschungsgruppe Village, Medizinische Universität Innsbruck

Mail: jean.paul@i-med.ac.at

## Co-investigators

**Ingrid Zechmeister-Koss**

Austrian Institute for Health Technology Assessment GmbH, Wien

Mail: Ingrid.Zechmeister-Koss@aihta.at

**Melinda Goodyear**

School of Rural Health/ Monash University, Melbourne

Mail: melinda.goodyear@monash.edu

**Annette Bauer**

Personal Social Services Research Unit, London School of Economics and Political Science, London

Mail: A.Bauer@lse.ac.uk

**Hanna Christiansen**

Institut für Klinische Kinder- und Jugendpsychologie, Philipps-University, Marburg

Mail: hanna.christiansen@staff.uni-marburg.de