EVIDENCE-BASED PRACTICE AND POLICES FOR IMPACT ON MENTAL HEALTH OF CHILDREN AND ADOLESCENTS

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Conflict of interest

All authors declare no conflict of interest in sense of the "Uniform Requirements of Manuscripts Statement of Medical Journal Editors"[1].

INTRODUCTION

The Ludwig Boltzmann Gesellschaft (LBG), a non-profit research organisation, addresses complex social challenges together with partners, by developing and testing novel forms of cooperation between science and non-scientific actors in a dynamic social environment. In this way, the LBG aims to develop economic and social solutions that positively support social change and can be used directly by civil society, politics and the private sector. LBG's "Research and Innovation Policy" emphasises the targeted and coordinated transgression of the boundaries of organisations, disciplines and systems (Open Innovation in Science) aiming to improve the societal impact of research. Thus, novel forms of engagement increase the opportunity to generate innovative problem-solving approaches.

In this case study, the "Village project", we investigate different measures aiming to drive evidence-based change, towards making a sustainable impact for children that have a parent with a mental illness. First, we introduce an innovative approach to engage the public in generating societal relevant research questions and establishing international and interdisciplinary "Research Groups" on mental health of children and adolescents. Second, we introduce educational programmes for researchers and adolescents to enrich research with meaningful youth engagement and transfer knowledge among different stakeholders and people with lived experience. Last, we focus on community engagement, awareness raising for mental health and working together with people with lived experience as game changers in advocating for informed decision-making on a community and policy level.

CREATING EVIDENCE-BASED PRACTICE USING A COLLECTIVE IMPACT FRAMEWORK

Aiming to generate societal impact in the field of "Mental Health of Children and Adolescents", LBG adopted a novel approach towards forming highly interdisciplinary "Research Groups". This aligns to the European Union's Horizon 2020 scheme (European Commission, 2013) to address society's "Grand Challenges" and recognises the central role social sciences and humanities can play through truly collaborative and additive research from multiple paradigms for research to create social impact (Maxwell and Benneworth, 2018). LBG's goal was to engage with different stakeholders and the public throughout the entire research process to develop novel solutions to challenges in the field of mental health, which directly impact society. Therefore, LBG started the "Open Innovation in Science" initiative, with the aim of systematically opening up processes of scientific discovery in an effort to enrich research, through new knowledge drawn from beyond traditional disciplinary boundaries.

ADDRESSING SOCIETAL RELEVANT CHALLENGES THROUGH PUBLIC ENGAGEMENT IN RESEARCH

Sauermann and Franzoni (2015) showed that user contribution in crowd sourcing is significant in magnitude and speed of crowd-sourcing knowledge. LBG's "Tell Us!"[2] was Europe's first crowdsourcing project, generating research questions on mental illness involving patients and family members and healthcare professionals. Four hundred high-quality contributions were analysed and clustered by an expert jury regarding their importance. Out of several important topics, securing mental health for children and adolescents emerged as a key issue. Additional interviews with experts in the field emphasised to focus on "children of mentally ill parents" emerging as the main topic.

Based on this result, LBG announced a research call representing an interactive workshop, "Ideas Lab"[3], to bring together 30 researchers for a multi-day event, during which researchers were specifically encouraged to think out-of-the box and dissolve disciplinary boundaries. Applicants were asked to complete an application via an online platform comprising six questions with regard to their professional background, expertise and interests contributing to realising the goal of the "Ideas Lab", and approach to team work. In total, 136 researchers applied to participate in the "Ideas Lab", and further assessment by the evaluators consisting of the mentors, an organisational psychologist and the programme mana-

ger. Thereof 30 applicants from a diverse range of disciplines had been invited to participate in the "Ideas Lab". During the 5-day event in Vienna, the researchers were supported by mentors, international experts representing a variety of pediatric and adolescent health fields, providing ongoing feedback on the development of project ideas in the "Ideas Lab". The mentors changed their role to become live peer-reviewers for the final presentations and project proposals on the last day of the "Ideas Lab" giving funding recommendations to LBG. Additionally, "provocateurs" or guest speakers, including international mental health researchers and experts by experience (young adults whose parents have a mental illness), were invited to inspire researchers and identify gaps in the mental health service system.

The LBG OIS centre developed novel evaluation criteria for the project proposal that were based on opening up disciplinary boundaries, fostering public engagement in the research process, and establishing new forms of stakeholder interaction and collaboration that lead to interdisciplinary and transdisciplinary research. These following criteria were applied to find innovative solutions to existing challenges in mental health by involving the public in the research process:

1. novelty, revolutionary and high-quality approach to complex challenges,
2. interdisciplinary research,
3. engagement, stakeholder/user engagement throughout the entire research process including dissemination activities and involvement of patients and family members in research activities,
4. feasibility, the capability to deliver their project as a high-quality interdisciplinary activity, provided both through the presentation of their joint proposal and their activity during the "Ideas Lab", and
5. impact, clear relevance to and the potential to make a distinctive and novel contribution towards addressing the research challenges in this area creating added value for society.

As a result of the "Ideas Lab", two "Research Groups", "DOT – Die offene Tür [The open door]"[4] and "Village – How to raise the Village to raise the child"[5] were recommended for funding with a combined budget of EUR 6 million during four years (2018-2021). To ensure public engagement and interdisciplinary research throughout the research process, the "Research Groups" are embedded in a dynamic network working closely with existing networks and patient organisations and are supported by a "Research Group and Relationship Manager" to foster community engagement and collective impact.

"RESEARCH GROUPS'" GOVERNANCE STRUCTURE

To empower people with lived experience in decision-making, we included their voices in the "Advisory Board" of the "Research Groups", which advises and evaluates the research activities twice a year. The

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2   www.redensiemit.org
3   www.ideaslab.lbg.ac.at
4   www.dot.lbg.ac.at
5   www.village.lbg.ac.at

"Advisory Board" consists of two academic experts in the field of mental health or specific methodologies within the project, an open innovation expert, a peer PI researcher, and two people with lived-experience. The recommendations of the "Advisory Board" are discussed and agreed upon by the "Steering Committee" including a representative of the LBG and the Medical University of Innsbruck (the "Village project's" university host organisation).

Besides traditional scientific measures, such as peer-review publications, dissemination and outreach activities, we introduced new assessment criteria regarding the meaningful engagement of public in research activities:

1. inclusion of people with 'lived experience' in research activities and community engagement,
2. co-development of interventions with stakeholders,
3. implementation and evaluation of their practice,
4. policy recommendation and engagement of policy makers in research activities,
5. up-scaling strategies for sustainable impacts for children and adolescents.

Additionally, to foster continuous engagement of people with lived-experience in the research process, we established the "Competence Group" as a new advisory body consisting of six young adults with lived experience ("Children of parents with a mental illness" – COPMI). This group consults both "Research Groups" on their research activities on a regular basis. In this way, we ensure the research supports inclusion of expertise based on own experiences. As a next step, governmental funding should be applied to increase awareness of valuable contribution of people with lived experience in research and sustainability of their work.

THE "VILLAGE PROJECT": CO-DEVELOPMENT WITH STAKEHOLDERS TO CHANGE PRACTICE

"Children of parents with a mental illness" (COPMI) often need additional supports to lead the happy and healthy lives they desire. However, in some cases, those supports are either not available or not found by families, resulting in negative long-term outcomes for these children. The "Village project" aims to increase identification and strengthen formal and informal supports around children when their parents have a mental illness (Christiansen et. al., submitted). This project will be co-developed with stakeholders and will implement and evaluate two practice approaches, focused on the child and on principles of collaborative care. A key challenge is that much of the 'hard' evidence of what works for whom, and what is good value for COPMI is largely lacking. In the light of this lack of evidence, it has been argued (Nicholson, 2009) that the following should be emphasised: involving practitioners and people with lived-experience as equal partners in research; the appropriate application of mixed-methods to explore the issues; and the development and application of appropriate child-specific outcome measures to better understand the needs and impacts on COPMI (focusing on child's self-esteem and resilience). After a scoping phase, synthesising the international evidence on barriers and opportunities for support for

COPMI, we will provide information on the mental health and social services within Tyrol in Austria, the project site.

Continuing public engagement in research to make an impact, the "Village" project aims to improve the situation of children who have mentally ill parents (COPMI) in Tyrol, Western Austria. In order to develop practice approaches to better identify and support these children and their parents, we needed an in-depth understanding of the regional Tyrolean characteristics in terms of existing support structures and the societal context in which they are embedded. This work was led by Col Ingrid Zechmeister-Koss, and the following welfare-state sectors were systematically analysed in terms of potentially relevant benefits: 'Health care', 'children/families', 'social affairs' and 'education'. The information on available benefits was firstly categorised according to welfare state sectors, and then synthesised into an overview of services that could be potentially relevant in the process of identifying and supporting COPMIs and their families (Zechmeister-Koss and Goodyear, 2018).

Tyrol is a region in the Western part of Austria, constituting nine political districts. From roughly 750.000 inhabitants, around 140.000 persons (19%) are dependent children (0-18 years). The vast majority lives in dual-parent families. Catholic religion plays an important role in Tyrol. 85% of Tyroleans are Austrian citizens. 50% of the population is actively working in paid employment, the remainder is either retired (20%), in education or in other forms of activity (parental leave, household leading only, military service). Regarding the identified benefits, both in-kind as well as cash-benefits are relevant. While benefits for children/families are mostly cash benefits with only limited publicly funded child-care facilities, in the other sectors, in-kind benefits (e.g. publicly paid health or social care services) are dominant. We identified a broad variety of benefits that may be utilised to identify and support COPMIs and their families. However, only one of the existing services (available in two districts) directly targets COPMIs. In terms of setting, a vast majority of services are office-based and a much smaller proportion of providers offer outreach services (e.g. in families' homes). The available services are characterised by a high proportion of public funding, however, access to publicly funded services may be restricted via gate-keeping (e.g. referrals from child and youth service) or shortage of capacities (e.g. psychotherapy, child care). The existing services show a geographical variation with more (types of) services available in the urban than in the rural regions. Services are characterised by high fragmentation in terms of governance (federal, regional, municipality), financing (taxes: federal, regional; social insurance) and service provision (public and private providers).

These results and a scoping of international best practice examples will inform the co-development phase with stakeholders in Tyrol, which will be made up of six co-design workshops which began in November 2018. During the co-development phase, we will develop practice approaches and tools to identify COPMI and to support them in everyday life by strengthening networks among formal and informal support systems in Tyrol. This will be supplemented with training material for implementing the practice approaches and thirdly, key-indicators for evaluating the practice approaches will be defined. The development of the practice approaches and evaluation indicators will be done in a participatory manner (co-design) involving representatives of stakeholders and particularly including people with lived experience. Community-capacity building approaches, concerned with developing a supportive network of allies around a person, utilising principles of collaboration, person-centeredness, and prevention, can increase resilience at an individual and community level, as well as be cost-effective (Knapp, Bauer, Perkins

and Snell, 2013; Wistow, Perkins, Knapp, Bauer and Bonin, 2016); how this relates to COPMI is not yet known, and this project will generate evidence to address this gap. A participatory and co-developed approach to the development of screening approaches and collaborative care, that is evidence-informed and evidence-generating, has not yet been implemented for COPMI – neither worldwide, nor in Austria. To this end, we will facilitate a series of design workshops with stakeholders at the study site to develop the components of the practice approaches based on the results from the scoping phase.

Practical efforts to initiate the practice approaches are central to the installation phase of implementation and include activities such as: developing the competence and confidence of staff through training and coaching in the new approach, as well as monitoring progress through regular check-ins and supervision of staff at study sites. The training protocol developed in the workshops will include the theoretical basis and underlying values of the programme, use adult learning theory, introduce components and rationales of key practices, provide opportunities to practice new skills to meet fidelity criteria, and receive feedback in a safe and supportive training environment. The length of training will be determined by the extent of change to the existing programme and practice model, but typically the face-to-face component will run over two days. A significant activity is to support each site in using the new practice approaches, as well as the research protocols. Champions of change will be identified during the workshops. These professionals, "Village facilitators", will be trained and supported to facilitate the formal and informal child-focused support. Once the new practice approaches and associated supportive systems are being used, strategies to promote continuous improvement and rapid-cycle problem solving will be applied. The research team will work with the study sites to use data to assess implementation progress, identify barriers, potential solutions, and drive decision-making.

An additional feature of this project is the central focus of understanding and listening to the 'child voice'. COPMI support in adult focused services has so far been mostly parent-centred, and not likely to identify or develop an evidence-informed support plan that meets the needs and listens to the 'voice' of the child. Incorporating the child's voice in practice approaches is likely to contribute positively to better outcomes, but this knowledge has not yet been developed. The importance of 'assent' and supporting children to develop their own 'voice' in healthcare is becoming increasingly recognised within the broader field of child health research. This follows the "United Nations Convention on the Rights of the Child" (United Nations. General, 1989), acknowledging the ethical imperative and rights for children to be provided with their own health information. Although research in healthcare communication is increasingly recognised as important in improving health outcomes, in both the areas of mental health and paediatrics, rigorous research investigating naturally occurring healthcare interactions involving the child is extremely limited. In particular, good healthcare service delivery is dependent upon clear and open communication between patients and their treating team. Improving communication within healthcare encounters can reduce medical errors, and act as a therapeutic lever to support patient empowerment (Roter and Hall, 2006). Limited research has shown that children retain some information better than their parents, and an increased proportion of

doctor-child communication compared to doctor-parent communication can increase parental satisfaction (Pantell, Stewart, Dias, Wells and Ross, 1982). For COPMI, these children may also not have the support of their parents in healthcare interactions. Consequently, supporting health professional-child communication could be argued to be even more important with COPMI to ensure children's concerns, needs, and wishes are discussed. This project provides a unique and valuable opportunity to investigate children's perspectives and interactive capacity within the COPMI setting, and to observe changes over time, in parallel with the broader interventions of this project. This project will importantly address knowledge gaps in this area and drive practice change. Evidence collected during the investigation of the 'child voice' will contribute to training approaches and inform the design of practice changes within the broader project.

EMPOWERMENT OF COMMUNITY AND LEADERSHIP

To empower patients, family members and the wider public to engage in research, LBG offers a public training programme "SCIENCE4YOUTH"[6] that was launched in September 2018 addressing adolescents and young people with lived experience. This programme aims to train adolescents scientific principles and methods in order to work as a co-researcher in research groups and teams. In a flipped-classroom approach (Moffett, 2015) with interactive video tutorials and quizzes, participants learn about the research process, how to apply open innovation in science (OIS) methods, develop their own research projects and apply their newly gained knowledge working together with the "Research Groups" (internships). Nineteen adolescents form high schools across Austria applied for the programme, thereof 16 females, that are mentored by pre and post doc researchers. Each mentor supports two mentees during the whole programme and development of their own research projects. Additionally, mentees are supported by a buddy system, each adolescent work in tandem with a peer. With this mutual learning approach, potentially new insights on how to actively involve the community in research will be established and the relationship between young people and researchers will be strengthened. These activities aim to empower youth, in order to establish youth leadership in mental health and develop youth partnerships with the government to make informed health decisions and be represented in national decision-making boards drawing on their experience and expertise.

COLLECTIVE IMPACT AND COMMUNITY ENGAGEMENT

A variety of routes can be applied to create change and impact for mental health practice and policies for children and adolescents. Besides providing rigorous scientific evidence and systematically increasing competences of individuals, it is critical to strengthen advocacy in order to raise awareness, identify and connect advocates and foster decision-

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6   www.ois.lbg.ac.at/en/methods-projects/science4youth

making processes to steer political change on many levels.

ADVOCACY

Raising awareness for the topic through multi-channel broadcasting activities is one of the main pillars to increase the potential for successful advocacy. This can be done through a variety of methods; however, crowdfunding is one of the main methods applied in this context that allows simultaneously raising money and awareness. In order to create successful crowdsourcing and crowdfunding campaigns, it is absolutely necessary to transform scientific messages into commonly understandable language with a clear scope and precise call to action. This approach will identify individuals who have not been aware of the topic before and reach individuals who are willing to support the implementation. Additionally, crowdsourcing helps researchers and practitioners to reflect on their own work and allows for new structures and approaches to emerge. Raising money and awareness is a complementary effort that will underpin the basis to strengthen and encourage advocates as a first initial step. Furthermore, creating awareness will lead to the representation of patients and people with (lived) expertise in decision-making boards that influence priority setting, making the topic more pressing and thus, relevant for political agenda setting and decision-making.

We will foster new ways of collaboration and structures among stakeholders that allow a cross-disciplinary exchange of practice and experience. Additionally, possible awareness campaigns in schools will inform and activate students and their families to find peer support providing self-help groups for COPMI, professional support and referral to specific networks. Further, we will engage with policy makers in our research activities early in the process to present evidence-based practice and strategies to upscale the project including people with lived-experience in the exchange.

VALUING COMMUNITY CONTRIBUTIONS

Engaging the general public in research is crucial to drive practice change to tackle socially relevant challenges. However, it is equally important to value the community's contributions and act on a level playing field to foster sustained engagement and collective impact. We envision capacity building activities that will be rewarded to maintain people's own development. For example, we will provide public space to inform and foster discussion about mental health between the public, researchers and people with lived-experience, create a peer network where people with lived-experience share their expertise, train interested people in research principles and public engagement, and foster community ownership by conducting youth/community-led research initiatives and projects. Close collaboration with stakeholders will be crucial to successfully drive these activities. An initial strategy to this end has already been initiated through the development of an online discussion forum hosted on the "Village project's" website[7]. These initiatives may be supported by additional governmental funding, cooperation with industry and donations.

In conclusion, creating evidence-based practice, using a collective impact framework and community engagement, will foster a sustainable impact on children and adolescents to truly drive system change. These activities will build capacity within a community, national and European level raising awareness of policy-makers on current challenges in mental health. Nevertheless, advocating for change on a community and policy level is key for successful implementation of system change thereby valuing communities' contribution and development in mental health.

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7   www.village.lbg.ac.at/getinvolved

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