

# **Mind the Gap Academy: Participative Medicine – Participative Democracy**

A Proposal for a Postgraduate Course to a Host University in Austria  
(to be identified)

Think-Tank  
for  
Participatory, Translational, Transcultural & Transdisciplinary Paediatrics  
= TT-4-ptttP

*Short Title: Mind the Gap*

*Lay Title:  
Global Citizen Struwwelpeter*

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| <b>Mind the Gap – the ptttP Approach –<br/>the different child with disruptive behaviours from a child-centered perspective</b> |  |
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| <i>Was wollen wir machen?</i>   | <ul style="list-style-type: none"> <li>○ <i>Plan:</i> Aufbau einer pädiatrischen Fortbildungsakademie mit (a) Aufbaustudiengang mit Diplom; (b) Masterstudium und (c) PhD-Programm</li> <li>○ Inhalt: Pädiatrische, sozialpädiatrische und kinder- &amp; jugendpsychiatrische Themenkreise aus der Perspektive der betroffenen Kinder- &amp; Jugendlichen (mit Bezugnahme auf die UNO Kinderrechtskonvention)</li> </ul>   |
| <i>Was ist neu oder innovativ?</i>  | <ul style="list-style-type: none"> <li>○ <i>“innovativer” Ansatz:</i> Themenkreise werden aus kindeszentrierter Sicht mit einem <i>partizipativen, translationalen, transkulturellen &amp; transdisziplinären</i> Ansatz betrachtet – Lehrende sind Praktiker/Kliniker/Wissenschaftler &amp; ‚Advokaten‘ (Mitglied der beteiligten Öffentlichkeit)</li> </ul>  |
| <i>Wie gehen wir vor?</i>   | <ul style="list-style-type: none"> <li>○ <i>Antrag an Fonds Gesundes Österreich</i> zur Erhebung der Bedürfnisse von Mitarbeiter*innen von im Gesundheits- und Bildungswesen via Town Hall Meetings / offene Veranstaltungen an den Universitäten, Schulen und Gemeinderäumlichkeiten, sowie Fokusgruppen Interviews mit Expert*innen und Kinder- Jugendlichen.</li> </ul>   |
| <i>Antragsteller an FGÖ</i>   | <ul style="list-style-type: none"> <li>○ <i>OI, SS, GK mit Advisory Board</i> (eingeladene Praktiker, Wissenschaftler, Direktoren, Professoren, Sozialarbeiter etc.)</li> <li>○ <i>Umsetzung:</i> Student*Innen Team (jeder Student/Ärzt*in hat einen Mentor aus dem Advisory Board, dadurch wird die orchestrierte Koordinierung der Erhebung und Harmonization der Lehrinhalte in allen Bundesländern gewährleistet)</li> </ul>  |
| <i>Fortbildungsakademie, Wie?</i>   | <ul style="list-style-type: none"> <li>○ <i>Methode:</i> Themenspezifischer Wissenserwerb durch fallbezogene Lehrmethodik mit Einbeziehung von Betroffenen (stakeholders) mit individualisierten, personalisierten und präzisions-medizinischen Lösungsvorschlägen.</li> <li>○ <i>Moduläre Struktur:</i> <ul style="list-style-type: none"> <li>○ Spezifische Vorträge (Fortbildungspunkte)</li> <li>○ Einheitliches ptttP Modul (Diplom)</li> <li>○ Grundmodul: ptttT Modul plus jeweiliger Themenkreis (Masterstudium)</li> <li>○ Fortgeschrittenes Module &amp; Forschung: Masterstudium &amp; PhD-Programm</li> </ul> </li> </ul>  |
| <i>Fortbildungsakademie, für wen?</i>   | <ul style="list-style-type: none"> <li>○ <i>Teilnehmer:</i> <ul style="list-style-type: none"> <li>○ Gesundheitsberufe, z.B. Sozial- und JugendarbeiterInnen, Mitarbeiter*innen von Ambulanzen, Ärzt*innen, Schulärzt*innen, Gesundheitspädagog*innen</li> <li>○ Bildungsbereich (Pädagog*innen, Museumspädagog*innen Lehrer*innen)</li> <li>○ Jugendarbeit (Kinder- und Jugendberater*innen, sozialpädagogische Kinder- und Jugendbetreuung, Seelsorger*inne, usw.)</li> </ul> </li> <li>○ <i>Befähigungsnachweise:</i> <ul style="list-style-type: none"> <li>○ Akkreditierte Fortbildungspunkte</li> <li>○ Diplom</li> <li>○ Akademischer Titel (Master/PhD)</li> </ul> </li> </ul> |
| <i>Mit wem?</i>   | <ul style="list-style-type: none"> <li>○ Fakultätsangehörige/r / Lehrkörper: lokal, national, international für Grundmodule und Themenkreise</li> <li>○ Präsentationen durch zwei Anchorpersonen (Fachperson &amp; Betroffene/r oder Advocate); Vielfalt durch digitales Lernen &amp; Beiträge von Fakultätsangehörigen / Lehrkörper &amp; Betroffenen</li> </ul>  |
| <i>Durch wen?</i>   | <ul style="list-style-type: none"> <li>○ Akademie in Kooperation mit einer oder mehreren Universitäten z.B. Meduni Wien, SFU Wien, DUK, Meduni Graz, Meduni Innsbruck, PM Salzburg, etc.</li> <li>○ Österreichische Ärztekammer</li> <li>○ Fachgesellschaften (ÖKJ, DGSP, EACD, IPSA, etc.)</li> <li>○ Krankenanstaltenverbände der Bundesländer</li> </ul>  |
| <i>Womit</i>  | <ul style="list-style-type: none"> <li>○ <i>Start via Finanzierungskonzept zur gemeinsamen Entwicklung des Curriculums &amp; Harmonisierung der Inhalte (z.B. Förderungsantrag an den Fonds Gesundes Österreich)</i></li> <li>○ <i>Zweite Stufe: Förderungen von BM für Wissenschaft &amp; Forschung, Stadt Wien, Stadt Graz</i></li> </ul>  |

|                           |  |
|---------------------------|--|
| Langfristige Finanzierung | <ul style="list-style-type: none"> <li>○ Einnahmen durch Fort- und Weiterbildungsveranstaltungen</li> <li>○ Spezialprojekte / Forschungsförderungen</li> </ul> |
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## Mission Statement & Motivation

Over the last three decades, we have experienced and witnessed the breathtaking changes in pediatric and psychiatric care for children and adolescents. Such changes mirror societal transformations in communities and have been driven by multiple discourses and negotiations, reflecting different, even contradictory perspectives.

For us, since 1989, the *Convention on the Rights of the Child*, an international human rights agreement setting out the civil, political, economic, social, health and cultural rights of children, has been guiding these necessary discourses and negotiations. Originally, the *Convention on the Rights of the Child*, is built, on the Geneva Declaration on the Rights of the Child drafted by Eglantyne Jebb, adapted in 1924 by the League of Nations and again re-worked and adopted in an extended form by the United Nations in 1959.

These adaptations are proving the ongoing need to re-visit the concept of child's rights in context with societal transformations. In the Academy Mind the Gap, Think-Tank for Transcultural Pediatrics, health care professionals with various training backgrounds are coming together for introducing a life-long continuous education program, for members of the medical and education systems and communities, within the framework of a postgraduate course to approach the 'different' child with 'different' behaviours in a participatory translational, transcultural, and transdisciplinary way. The title Mind the Gap invites us all to reflect our thinking and acting. All lectures, seminars, self- and group learning exercises are built on the *Rights of the Child* and driven by the main leitmotif question *are we offering the best care for the best interest of the affected individual?* We deeply believe that the discourses around this leitmotif question will bring not only involved stakeholders (e.g. parents, teachers) and communities but also the children and youth together under an applied ethics framework and exceed nation, population and religion based limitations.

# Leitbild & Motivation

In den letzten drei Jahrzehnten erlebten wir die atemberaubenden Veränderungen in der pädiatrischen und psychiatrischen Versorgung von Kindern und Jugendlichen. Veränderungen spiegeln gesellschaftliche Transformationen bzw. der gelebten Kultur wider. Solche Veränderungen werden von unterschiedlichen Diskursen und Prozessen vorangetrieben, die manchmal auch widersprüchliche Perspektiven widerspiegeln.

Seit 1989 leitet die Konvention über die Rechte des Kindes, ein internationales Menschenrechtsabkommen, diese notwendigen Diskurse und Verhandlungen mit Fokus auf die zivilrechtlichen, politischen, wirtschaftlichen, sozialen, gesundheitlichen und kulturellen Rechte. Die Konvention über die Rechte des Kindes basiert auf der Genfer Erklärung über die Rechte des Kindes, ausgearbeitet von Eglantyne Jebb, adaptiert vom Völkerbund (1924) und 1959 von den Vereinten Nationen nochmals überarbeitet und anschließend verabschiedet.

Diese Anpassungen beweisen die Notwendigkeit, das Konzept der Kinderrechte im Kontext gesellschaftlicher Transformationen immer wieder zu überdenken und ggf. zu adaptieren. Die geplante *Mind the Gap Akademie*, dem Think-Tank für transkulturelle Pädiatrie, versteht sich als ein Forum, in dem Angehörige der Gesundheitsberufe mit unterschiedlichem Ausbildungshintergrund zusammenkommen, um genau diese soziokulturellen Veränderungen bei der pädiatrischen Ausbildung, Lehre und Forschung zu berücksichtigen. Das Ziel ist ein lebenslanges Weiterbildungsprogramm für Mitglieder aus der Medizin und dem Bildungswesen, sowie den betroffenen Gemeinschaften im Rahmen eines Aufbaustudienganges auszuarbeiten und anzubieten. Grundlage dafür ist ein partizipatives translationales, transkulturelles und transdisziplinäres Denken, um das „andere“ Kind mit „unterschiedlichen“ Verhaltensweisen gemeinsam verstehen zu lernen. Der Titel *Mind the Gap / Achtung Spalt* lädt uns alle ein, unser Denken und Handeln kritisch zu reflektieren. Alle Vorträge, Seminare, Selbst- und Gruppenlernübungen basieren auf dem Konzept der Kinderrechte und der Hauptfrage: Bieten wir die bestmögliche Intervention im Interesse der jugendlichen Betroffenen? Wir sind der festen Überzeugung, dass dieser Diskurs nicht nur alle beteiligten Stakeholder und Gemeinschaften, sondern auch die Kinder und Jugendlichen unter dem Dach, der angewandten ethischen Rahmenbedingen

zusammenbringen wird und die engen grenzensetzenden Diskussionen in Bezug auf Nation, Bevölkerung und Religion überwinden wird.

## Overview

***The different child.*** During the last centuries, human sciences have developed a new advanced understanding of biological, physical and developmental characteristics that distinguish children and adolescents from adults. In recognition of the medical diversity of child health and disease, pediatrics has been established as an independent medical specialty; in consequence, pediatric health care programs have led to a significant reduction of infant morbidity and child death. Providing advanced therapies for chronic conditions and allowing early recognition of risk through prevention programs has led to an unprecedented improvement of long-term outcomes. Yet, inequalities in access to such advancements and uncertainties around personally meaningful benefits demand a critical appraisal of medical interventions opening up opportunities of alternative approaches. Deciding and acting in the best interest of the child depends not only on parental authority, but also on cultural agreements, societal conventions and medical reasoning. The worldwide increase in the use of behavior modifying psychopharmacological therapies for children with problem behaviors and related mental health issues is only one example how parental ownership and societal paternalism may stand in conflict with the child's right to be different from the norm and how problem behaviours are seen, interpreted and rated. In our global but multicultural societies with increasing educational and economic diversity, decision-making due to societal pressure will become the rule rather than exception. *Mind the Gap* – Think-Tank for Transcultural Paediatrics is supporting the recognition and management of medical and non-medical causes of being a 'different child' and 'problem behaviours' using a participatory, translational, transcultural, and transdisciplinary (ptttP) approach.

## Überblick

**Das andere Kind.** Während der letzten Jahrhunderte haben die Human- und Naturwissenschaften ein besseres Verständnis bez. der biologischen, physikalischen und entwicklungsneurologischen Merkmale geschaffen, die Kinder und Jugendliche von Erwachsenen unterscheiden. In Anerkennung der medizinischen Vielfalt von Gesundheit und Krankheit bei Kindern wurde die Pädiatrie als eine eigenständige medizinische Fachrichtung etabliert. In Folge haben pädiatrische Gesundheitsprogramme zu einer signifikanten Verringerung der Morbidität und Mortalität von Kindern geführt. Die frühzeitige Erkennung von Risiken durch nationale Präventionsprogramme und die Zurverfügungstellung neuer Therapien für chronische Erkrankungen brachten eine beispiellose Verbesserung der Lebensqualität der Betroffenen. Ungleichheiten beim Zugang zur medizinischen Grundversorgung und Unsicherheiten in Bezug auf die Behandlungserfolge bei Betroffenen erfordern jedoch eine kritische Bewertung medizinischer Interventionen. Denn die Entscheidung und das Handeln im besten Interesse des Kindes hängt nicht nur von der Autorität der Eltern ab, sondern auch von kulturellen Vereinbarungen, gesellschaftlichen Konventionen und medizinischen Überlegungen. Die weltweite Zunahme von verhaltensmodifizierenden psychopharmakologischen Therapien für Kinder mit Verhaltensstörungen und damit verbundenen psychischen Gesundheitsproblemen ist nur ein Beispiel dafür, wie elterliche Eigenverantwortlichkeit und gesellschaftlicher Paternalismus im Widerspruch zum Recht des Kindes stehen kann. Vor allem dann, wenn die Abweichung von der Norm (bzw. die Krankheitswertigkeit einer bestimmten Verhaltensweise) unterschiedlich gesehen, interpretiert und bewertet wird. Die individuelle versus systemkonforme Entscheidungsfindung wird in unseren globalen, aber multikulturellen Gesellschaften mit zunehmender Bildungs- und Wirtschaftsvielfalt, aufgrund des gesellschaftlichen Drucks, zu einer Gratwanderung. Mind the Gap - Think-Tank für transkulturelle Pädiatrie unterstützt die Erkennung und

Behandlung von medizinischen und nicht-medizinischen Ursachen für das sogenannte „andere Kind“ sowie für „Problemverhalten“ mithilfe einer partizipativen, translationalen, transkulturellen und transdisziplinären (ptttP) Ansatzes und baut diese Diskussion auf die Kinderrechtskonvention auf.

**Problem Behaviours.** Children, adolescents and young adults with intellectual disability, but also geriatric patients with dementia often present with *problem behaviours*, perceived as *distinctive atypical, sometimes unique, challenging and/or disruptive*. For the family, their caregivers and their community, such behaviours are usually of major concern, stress and distress. As recognizable patterns, *problem behaviours* share ubiquity and exist in many contexts and cultures, but may have *different causes and different* interpretations. Confronted with problem behaviours, most of us professionals share affected families / caregivers concerns, stress and distress; in consequence, we tend to review what can be done *immediately* to stop such problem behaviours. However, interpretation of signals, gestures and behavioural cues happen in a cultural context. Thus, developing trust, applying naturalistic observations and exploration of problem behaviours and their meanings are the foundation of good practice in the educational and medical systems. And yet, in clinical practice, recognition, interpretation and treatment of problem behaviours vary depending on the training background of the involved professionals.

**The goal of the Mind the Gap** -- Think-Tank for Transcultural Paediatrics is to implement and disseminate the skill set for thinking and acting within a ptttP-framework. This will support the recognition and management of medical and non-medical causes of *atypical, unique, challenging and/or disruptive behaviours* in a sensitive and culturally appropriate way. The target audience includes providers in clinical and non-clinical settings, including advocates from the school system who require continuous education credits. The narrative-based teaching concept will support the implementation of high quality, international knowledge, following ubiquitous ethical standards (framed by the Child Right Charter: United Nations Convention on the Rights of the Child), in chronic care management, reaching out to the school system and (otherwise ignored) communities. To guarantee independent and sustainable financial resources, this academy concept is proposed to the host university (to be identified) as an in-person / digital postgraduate

course (with separate to attend blocks) in collaboration with partner universities.

**Problemverhalten.** Kinder, Jugendliche und junge Erwachsene mit geistiger Behinderung, aber auch geriatrische Patienten mit Demenz weisen häufig problematische Verhaltensweisen auf, die als atypisch, manchmal charakteristisch einzigartig, herausfordernd und / oder störend empfunden werden. Solche Verhaltensweisen haben für die Betroffenen, ihre Familien und ihre Betreuer sowie für die Gemeinschaft, in der sie leben große Bedeutung, weil sie Stress und Verzweiflung verursachen können. Problemverhalten und ihre Erkennungsmerkmale existieren in allen Kulturen, jedoch sind sie oft kontextbezogen und können unterschiedliche Ursachen haben und damit unterschiedliche Interpretationen bewirken. Konfrontiert mit Problemverhalten teilen die meisten Fachleute, den Stress, die Bedenken, ja sogar die Verzweiflung bzw. Not der betroffenen Familien/Betreuer. In Folge neigen Fachleute dazu das Problemverhalten zu stoppen, ohne sich über deren „tieferen“ Sinn Gedanken zu machen. Denn, die Interpretation von Körpersignalen, Gesten und Verhaltensmerkmalen erfolgt jedoch in einem erlerntem Kontext. Deswegen variieren in der (klinischen und bildungspolitischen) Praxis die Erkennung, Interpretation und damit die Behandlung von Problemverhalten je nach Ausbildungshintergrund der beteiligten Fachkräfte.

**Das Ziel des Mind the Gap** - Think-Tanks für transkulturelle Pädiatrie ist es, die Fähigkeiten zum Denken und Handeln in einem ptttP-Rahmen umzusetzen, implementieren und zu verbreiten. So soll das Erkennen und die Behandlung medizinischer und nichtmedizinischer Ursachen von Problemverhalten auf kulturell angemessene und sensible Weise unterstützt werden. Die Zielgruppe der Ausbildung umfasst Fachleute in klinischen, nichtklinischen Arbeitsbereichen, einschließlich MitarbeiterInnen im Schulsystem, und MitarbeiterInnen der nichtstaatlichen Institutionen (non-governmental organizations). Die auf narrative Erzählkonzepte aufgebaute Lehre, wird die Umsetzung von Up-to-Date Wissen nach hochwertigen ethischen Standards

unterstützen (festgelegt durch die Kinderrechtscharta: Konvention der Vereinten Nationen über die Rechte des Kindes). Gerade bei der Behandlung chronischer Erkrankungen und Integration im Schulsystem werden (ansonsten marginalisierte) Gemeinschaften profitieren.

***What is the utility of this course for society?***

A better understanding of causes and interpretations of *distinctive problem behaviours* will have implications both in the school system and clinical settings, and beyond. The most striking reality is that reducing concerns, stress and distress of affected people, patients / patient families / caregivers and professionals, will increase their emotional and physical well-being, and quality of life. This in turn may reduce marginalization of individuals who present in ways that are not considered to be the 'norm' in modern society, ultimately contributing to a sense of inclusion, integration and prevention.

***Was ist der Nutzen dieser Ausbildung für die Gesellschaft?***

Ein besseres Verständnis der kausalen und potenziellen Ursachen von Problemverhalten, sowie die Vermeidung von subjektiven oft falschen bzw. eingeschränkten Interpretationen, wird mannigfaltige Auswirkungen haben: auf Compliance und Adherence, sowie der Patienten- und Angehörigenzufriedenheit aber auch darüber hinaus, z.B. auf das Schulsystem und deren kulturelle Integrationsaufgaben. Die auffälligste Erkenntnis ist, dass die Verringerung von Sorgen, Verzweiflung und damit assoziierter Stress bei Betroffenen, Patienten / Patientenfamilien / Betreuern, aber auch bei Fachleuten und Therapeuten das emotionale und körperliche Wohlbefinden, sowie die Lebensqualität erhöht. Dieses Wohlbefinden, kann wiederum die Marginalisierung von Personen, die in der modernen Gesellschaft nicht als „Norm“ entsprechend angesehen werden reduzieren, und damit letztendlich zu einem Gefühl der Inklusion, Integration und Prävention beitragen.

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## **Attachments**

- (1) Background
- (2) Framework
- (3) Target Audience & Organization

DRAFT February 2021

## (1) Background

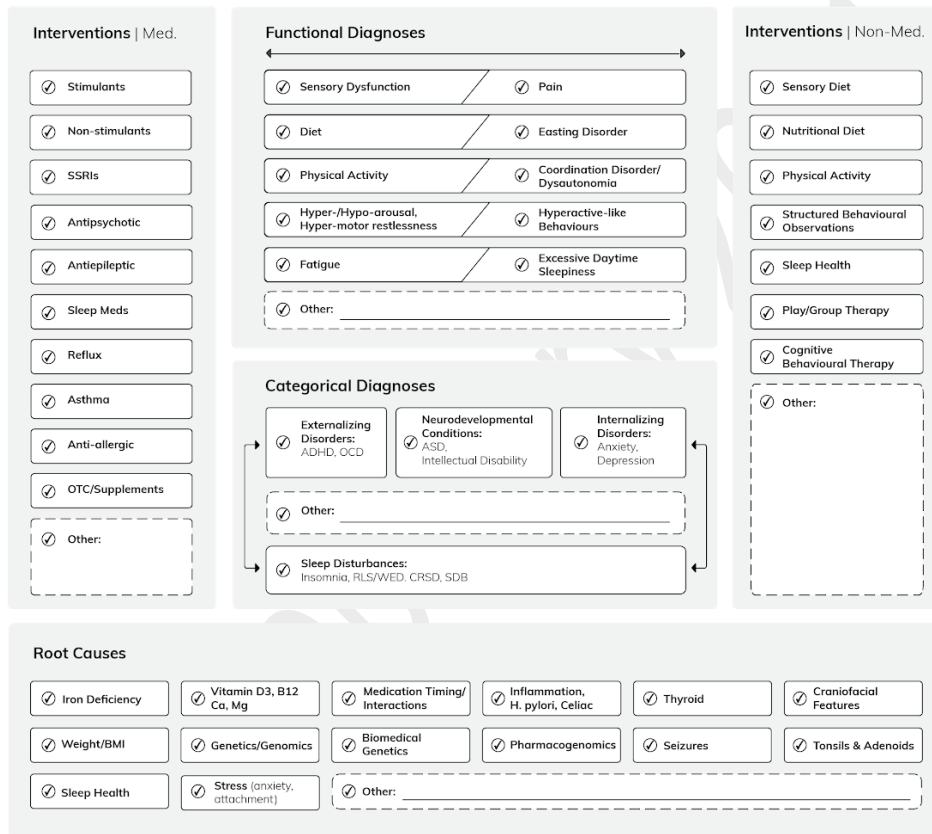
**Neurodevelopmental disorders and mental illness** together are the most common non-communicable diseases in Europe, which require chronic care management. Despite the fact that approximately 20% of the overall pediatric age group requires up to 80% of the health care expenses, continuity of care is broken and in consequence, affected individuals and their families are at risk of getting ostracized. Education, values, family structure, and socioeconomic situation have an impact on compliance / adherence, defined as a specific type of behaviour that has been discussed during the therapy and recommended as beneficial. Medical / socio / emotional / psychological factors affect action, reaction, and outcome in the healing process; in the best case, we speak of *individualized successfully tailored therapies* versus a more commonly employed ‘*one size fits all*’ approach, which is considered to be inefficient and may even cause more harm than benefit. **COVID-19 induced clinical and educational shutdowns**, shortage of work and/or unemployment have destabilized regular settings. Many affected patients are in crises while the ability of the healthcare system to provide much needed services in a flexible way and improve or maintain compliance / adherence is impaired. Furthermore, surveillance concepts to investigate the dimension of impairments are missing. **These two considerations have been our starting point for reflecting ongoing rapid system transformations in pediatric and psychiatric child and adolescent services** (e.g. from face-to-face to telehealth / -medicine).

**Characteristics of the affected populations.** Children, adolescents, and young adults with neurodevelopmental disorders and/or mental illness are often diagnosed with Autism Spectrum Disorder (ASD), prenatal alcohol exposure/fetal alcohol spectrum disorders (PAE/FASD), genetic conditions, and intellectual disability or uneven profiles (discrepancies in abilities). They may show a variety of functional diagnoses like sensory dysfunctions, hyper-arousability and hyper-motor restlessness, elevated pain threshold, coordination challenges affecting physical activity, fatigue and daytime sleepiness, monotonous diet or eating disorders, due to overshadowed and not recognized root causes (see Figure 1, Logic Model), all together resulting in behavioural cues perceived as unique, atypical, uncommon and/or disruptive behaviours.

**Involving communities in the management of patients with neurodevelopmental disorders and mental illness is complex.** Members of the medical and educational systems who conduct the intersection management, need to be connected with each other, speak a mutually shared language, and receive the tools for grounding their suggestions in the culturally diverse communities of the affected individuals and their caregivers. Each patient’s narrative is unique, thus requiring an individualized approach. Similarly, treatment options that build on in-depth knowledge need to be communicated in a culturally sensitive way to address the needs of the patient and caregiver family. Hence, patients and caregiver families are an important stakeholder in this shared language development endeavour and need to be integrated in all medical and educational considerations to avoid overshadowing or dismissing reported symptoms (see Figure 2, patients in complex care management). Even minor communication problems can aggravate, independent of educational or ethnic background, affected individuals’ trends for segregation and ghettoizing, thus transparent and inclusive communication are core for prevention.

**The Solution – Life Long Learning.** We suggest the creation of a *sustainable long term network as an international academy*, which explores and applies, together with the involved stakeholders via an open access key-note lecture series and training modules (offered as post graduate courses, guaranteeing sustainable funding), tailored and culturally sensitive best of care options for

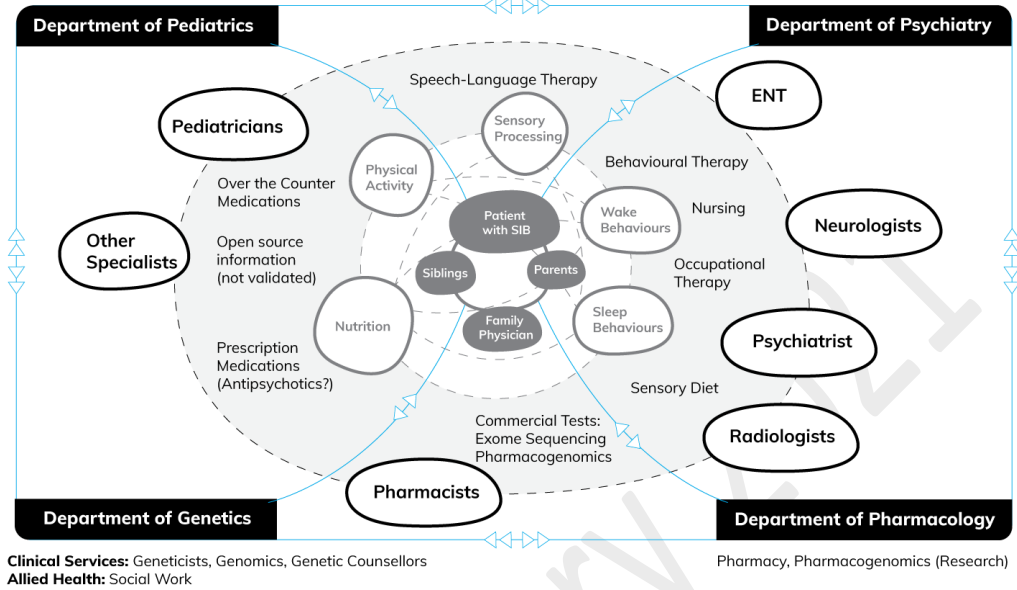
individuals in need. The collaboration of professionals all working in academic clinical and non-academic community based professionals in urban, sub-urban, and rural locations puts us in the unique position to create, and evaluate the suggested strategy using a participatory *trans*-cultural, *trans*-disciplinary and *trans*-diagnostic approach for reviewing (categorical and functional) diagnoses, possible root causes and the multiple medical and non-medical intervention options. **A key part of the evaluation will be the development of surveillance measures that can be linked with administrative data. This will enable us to adapt to changes in clinical practice emerging (as experienced during this pandemics), and become a learning system, consequently able to react faster with more flexibility.**



**Figure 1** shows the clinical logic model, which supports a framework for implementing a *ptttP* approach to recognize the various medical and non-medical causes of disruptive behaviours in a sensitive, culturally appropriate and medically grounded way.

**Clinical Services:** Biomedical Diseases, Complex Pain, ENT, Gastroenterology, Neurology, Radiology, Respiratory, Sleep Program, Translational Therapeutics  
**Allied Health:** Dietitian, Nursing, OT, PT, Social Work, Various Labs

**Clinical Services:** Liaison w/ Pediatric Sub-Specialties, Neuropsychiatry, SIB Clinic  
**Allied Health:** Dietitian, Nursing, OT, PT, Social Work



**Figure 2** shows the complexity of organizational structures for patients with the leitmotif of being 'different', e.g., with the diagnoses autism spectrum disorder (ASD), prenatal alcohol exposure/fetal alcohol spectrum disorders (PAE/FASD) and rare diseases and genetic conditions as the most frequent causes of uneven profiles and/or intellectual disability, requiring multiple services.

## (2) Framework

**The title of the endeavour, *Mind the Gap. Think-Tank for Transcultural Paediatrics***, invites to re-think current service delivery and how we deal with the different child in the context of neurodevelopmental disorders and mental illness. Thinking broader, also the concepts of *in-* and *exclusion* in community settings have to be re-visited and re-thought. Research has demonstrated that for improving quality of care the *ptttT* approach is the most efficient strategy. Understanding and acknowledging one's counterpart to be different and having different needs improves communication and negotiation of interventional goals. The creation of a respectful communication environment without imposing one's will on the counterpart, improves in therapeutic interactions, motivation, thus participation, adherence and engagement. This collaboration of stakeholders is the core strategy for stopping marginalization of culturally different communities and integrating transcultural thinking and acting in knowledge dissemination. *The major goal of the proposed postgraduate course is to create the urgently needed room for brainstorming, re-thinking, re-visiting, and re-searching how to implement* (based on the United Nations Convention on the Rights of the Child) *the most efficient, tailored, therapeutic strategies for personalizing care, increasing adherence and improving quality of life.*

**The nickname, *Global Citizen Struwwelpeter***, references the book *Struwwelpeter* (by Heinrich Hoffmann a general practitioner, who later on became a psychiatrist), which depicts different behavioural patterns that were discovered, approximately 100 years later, as textbook characteristics of disruptive child behaviours (see figure 3 *Struwwelpeter*). The cartoons are based on observations and pattern recognition and allow a grounded, but culturally sensitive discussion on how *challenging* or *disruptive* might be perceived and dealt with in different settings, as the book was translated in more than 35 languages and has spearheaded a discussion on its appropriateness as a children's book bridging from paediatrics to educational psychology and the education system. Very recently, the authors of this proposed postgraduate program have been invited to approach *disruptive behaviours* from a *sleep and wake perspective* and spearhead a new approach in the fields of pediatrics, mental health and child and adolescent psychiatry (<https://www.frontiersin.org/research-topics/16928/sleep-vigilance-disruptive-behaviors>).

**The unique strategic mandate of the proposed Academy is to establish the space for being 'different' in communities and a tier systems framework for guaranteeing a collaborative step by step work-up of disruptive behaviours in the medical and educational systems.** All offered course themes will be presented in a publicly available key-note lecture series, while the course content will be built on three levels of knowledge: first an introductory level will address professionals working in the community; at the advanced levels I & II, professionals working in community hospital/centre settings and the next higher specialized level (teaching or university hospitals) will be addressed, respectively. All sessions are built on case vignettes and case series. The blocks will integrate knowledge about the underlying categorical and functional diagnoses, possible root causes, which include differential diagnostic considerations as well as intervention strategies.

**Setting.** While in an ideal world, seminars are imagined to happen in an inspiring environment in a segregated place with a restricted number of participants meeting faculty and having academic chimney talks, the COVID-19 crisis has again magnified the real life situation. Professionals are again working hard at their limit and do not have much capacity to attend even virtual

conferences. Therefore, **new knowledge dissemination concepts must also be prepared as e-learning modules compatible and palatable for exhausted professionals.** Thus, we are suggesting two, two-hour seminars, which can be reviewed with subscription multiple times within one month and professionals can attend courses whenever it works for them after subscribing. A joint discussion time once per month for each block and possible meetings of several block participants will support meetings of participants with faculty and the creation of an academic network as a *Think - Tank*.

**Why Narratives in Teaching?** Communication errors cause discontinuity in care and result in pitfalls that are usually analyzed with blame and shame. This increases the burden for those who work with empathy (up to burn out and depression) as well as aggravates professional's reactive thinking and acting. In contrast, our approach will bring members of the medical and educational systems, who work with patients with different up to disruptive behaviours, together and allow for urgently needed new quality improvement initiatives as comparisons set benchmarks. The case vignettes will describe the experienced narratives of children, adolescents, and young adults from medical / socio-cultural / psychological perspectives and review how neurodevelopmental disorders and / or mental illness are approached in different cultural settings, as already done by Heinrich Hoffmann in 1844 and neutralize the burden of the discussion. To achieve this goal, *all training modules use a narrative approach (based on case vignettes) investigating challenging or disruptive behaviours in environmental thus cultural contexts, reviewing the suggested approaches and therapeutic intervention strategies from multiple perspectives and how compliance/adherence can/could/should be achieved.*



Figure 3. Struwwelpeter with a mask in times of Covid crisis and a Struwwelpeter puzzle. Courtesy of the Struwwelpeter Museum (Frankfurt, Germany) - please note that for this postgraduate course, the *Frontiers in Psychiatry* project as well as funding applications are done in a strategic partnership with the Struwwelpeter Museum.

### (3) Target Audience & Organization

**Target Audience** are professionals with a health care / education / social work background, as well as patient and community advocates with a professional background representing non-governmental organizations, who will help to implement and apply the suggested knowledge. The aim of this postgraduate course, consisting of multiple practice oriented blocks is, harmonization of various clinical approaches and the creation of circumscribed pTTT approaches to complex clinical syndromes and presentations. Faculty members will utilize shared case vignettes and case series for agreeing with each other how 'harmonization' within the proposed United Nations Convention on the Rights of the Child ethics framework should be applied and how knowledge should be disseminated. Our goal is to identify intersections where pitfalls in diagnosis happen and / or symptoms are overshadowed. This is central, as once overshadowed symptoms are identified and treated, wellbeing and quality of life of the affected individuals' and his / her caregivers' significantly improves.

**For the advisory and scientific board**, national and international professionals will be invited based on social, academic and/or scientific merits and patient advocates will be recruited via NGOs working at national and/or international level (e.g. FASD Europe, European Academy of Childhood Disability; RLS-Germany) – this will guarantee transparency from the scratch and implementation of the courses not only at local and national but also at international level.

**Course curriculum** consists of 2 modules, each of them consisting of 10 ECTS (European Credit Transfer System), all together 250 hours of teaching per semester for four semesters (1000 hours of teaching). Each block (except the introduction block but also that might change) includes seminars at two different levels, introduction and advanced, respectively; presentations are given by at least one (often multiple) *expert presenter(s)* (chosen based on [clinical] experience, research and publications) and one or multiple 'Advocate(s)'. Additional facultative clinical blocks offer continuous medical education credits to approach clinical syndromes at an introductory or two advanced levels. These clinical blocks will be developed and mentored in collaboration with national, European and International bodies.

**An Advocate** is defined as a member of the involved communities. Involved and invited communities are *stakeholders* from non-governmental and governmental organizations, they might be individuals working as caregivers (birth-/adoptive/foster families), and/or at different levels in nursing, therapies, social work, medicine, psychology, education system, and most importantly from organizations representing different cultural heritages, ethnic minorities. An advocate in module I may receive an honorarium but will be not an official part of the faculty, whereas advocates in module II will be an official member of the teaching faculty and may receive an honorarium (if not salaried by a governmental organization or partner organization). Advocates might also be individuals working at different levels in nursing, therapies, social work, medicine, psychology, education system but also as caregivers (birth- / adoptive- / foster-families), and most importantly be sent by organizations representing different cultural heritages, ethnic minorities as their members are often underserved populations in the health care system. With this strategy, we will involve communities from non-governmental and governmental organizations as stakeholders and guarantee dissemination in clinical / school / social work practice applicable knowledge.

**The aim of the interactive expert-/advocate-tandem teaching concept at the introductory and also advanced levels**, is to challenge presented academic concepts and allow us to review how implementation in diverse settings would work. The 'tandem' teaching concept will guarantee that the course content is grounded and also palatable for practitioners working outside the academic setting of hospitals or social sciences research. For finding and motivating the right *local and international* 'advocates', we will establish a bursary, for which participants can apply; awarded participants will receive a discount of approx. 50%. These bursaries may be awarded by stakeholders (e.g., health authorities, educational system and strategic partners, e.g. cities in cooperation agreements with Vienna on specific issues for a limited time).

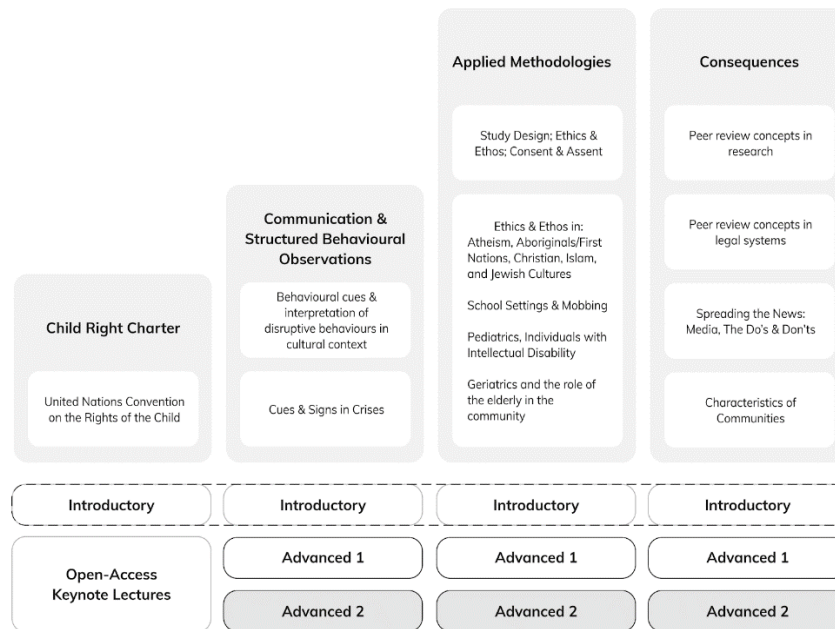
**The course language** will be initially in German, as the content is developed *in* Vienna, a 2 million city seen internationally as an exemplary role model for Europe positioned at the top of quality of life charts. 41% of the residents of *Vienna* are of foreign origin, among them many health care professionals and children and adolescents, the next generation of professionals, who at some point might also work in health care, educational and/or social services.

**An online teaching concept** will be developed for allowing participants from other locations than Vienna and Austria to participate in these courses. Based on feedback of attendees of the courses, we will make adaptations and further develop the course content in English. Presentations may include optional 20-30 min video recordings of researchers spearheading a certain theme in a narrative review format (in their mother tongue, for an international audience translated in English), and contributing to one special aspect of the presented theme. Up to 35 participants can register for one course (ideally <20). Depending on academic interest's eligible participants can register in addition to the introductory course (for starters) also for the advanced in-depth version and conduct directed studies and write a thesis for achieving a Master of Science degree.

**Content** will be presented in of 40+ blocks per module; each block includes two two-hour seminars; presentations are given by at least one (often two) expert presenter(s) (chosen based on [clinical] experience, research and publications) and one or multiple 'Advocate(s)' (90 min plus 30 min of discussion time). In the e-health learning options the 30 mins. of discussion time will be accumulated to a joint one to 1-1.5 hour video conference discussion once per month for the subscribers of each block.

**Course or Module I. Applying the Participatory Transcultural Approach.** Introduction & Creating the Framework. (Course Language: German / English). The attendance of all introductory levels is mandatory for achieving a diploma, Master or PhD degree. *Target Audience:* professionals with a health care and education background, as well as patient and community advocates representing non-governmental organizations. For integrating advocates without academic eligibility a special certification as guest visitors is suggested.





**Figure 4** Overview of Course I. Applying the Participatory Transcultural Approach. For achieving a diploma, Master or PhD degree the attendance of all introductory levels is mandatory.

Transcultural thinking and approach will be presented integrated in the following frameworks (see figure 4):

- I. Child Right Charter: United Nations Convention on the Rights of the Child**
  - Struwwelpeter et al; Pinocchio and friends;
  - Analyses of children's books, songs, toys by experts, strategic partners (e.g. Struwwelpeter Museum, Nürnberg Spielzeugmuseum, ZOOM Kindermuseum Wien, Museo Pinocchio e Dante in Florence etc.)
- II. Communication & Structured Behavioural Observations**
  - Behavioural cues & interpretation of disruptive behaviours in anthropological, medical and cultural context
  - Cues & Signs in Crises
- III. Applied Methodologies**
  - Study Design; Ethics & Ethos; Consent & Assent
  - Ethics & Ethos in:
    - Atheism, Aboriginals/First Nations, Christian, Islam, and Jewish Cultures
    - in School Settings & Mobbing
    - in Pediatrics, Individuals with Intellectual Disability
    - in Geriatrics and the role of the elderly in the community
- IV. Consequences**
  - Peer review concepts in research
  - Peer review concepts in legal systems

- Spreading the News: Media, The Do's & Don'ts
- Characteristics of Communities

**Course or Module II with multiple Sub-Modules. Applying the ptttP Approach.** All sub-modules represent the three levels of knowledge (introductory, advanced 1 and 2) and will focus on clinical syndromes and functional diagnoses. (Course Language: English). The attendance of all introductory levels in Course I is mandatory for achieving a diploma, Master or PhD degree with the content of course II and its sub-modules. *Target Audience:* professionals with training in nursing, therapies and medicine (for sub-modules), as well as patient and community advocates representing non-governmental organizations and the education system (for Course/Module I).

Blocks will be developed for the following main theme: *medical and non-medical Interventions in Pediatrics and Child & Adolescent Psychiatry – for treating challenging and/or disruptive Wake & Sleep-Behaviours for the age groups* (see figure 5)

- I. **Children < 5 years of age**
- II. **School aged children 6-12**
- III. **School aged children 13-19**
- IV. **Young adults**

Patients from the four age groups may have been diagnosed with:

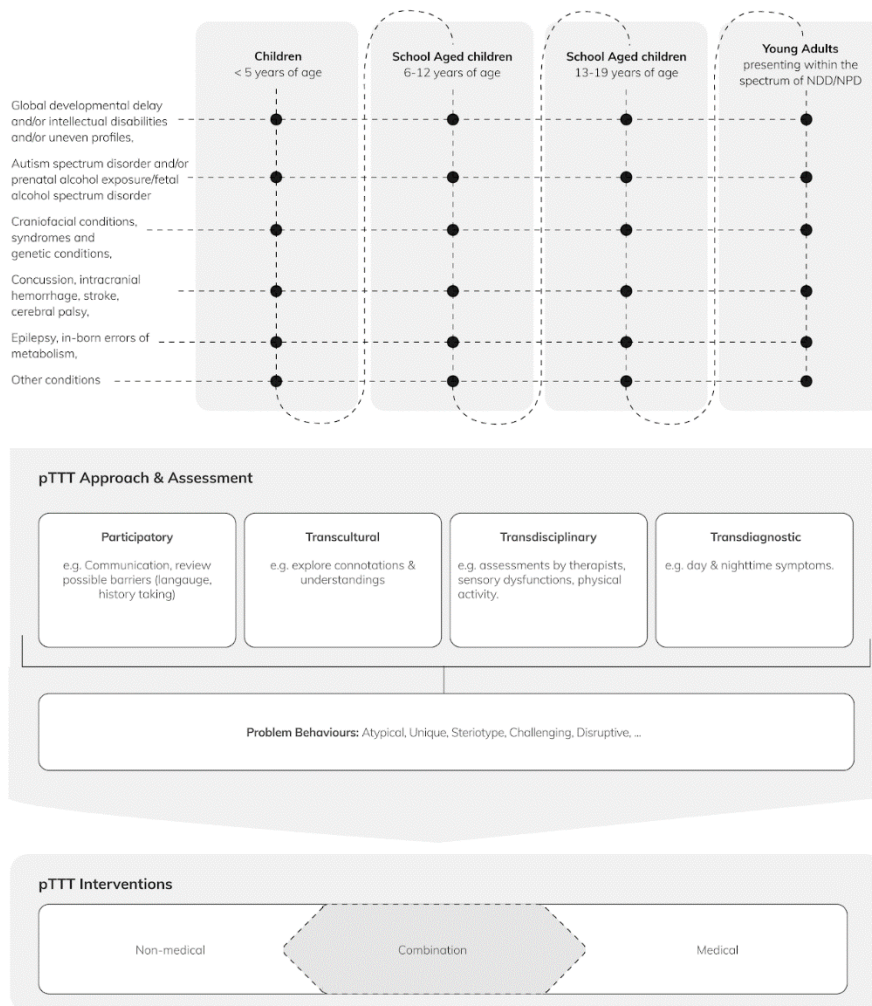
- uneven profiles (incl. being gifted), global developmental delay and/or intellectual disabilities
- autism spectrum disorder and/or prenatal alcohol exposure/fetal alcohol spectrum disorder
- craniofacial conditions, syndromes and genetic conditions
- concussion, intracranial hemorrhage, stroke, cerebral palsy
- epilepsy, in-born errors of metabolism
- or other conditions not listed here

Content regarding disorders and syndromes, their assessment and interventions will be presented utilizing the pTTT methodologies applied in behavioural sciences, allied health professionals and medicine and will be built on social-cultural context, with an introductory and advanced I levels. Note that advanced II is reserved only for trainees conducting a Master and/or PhD program.

- I. **Foundational & In-depth Knowledge re Focused Disorders and Syndromes**
- II. **Assessment: Creating the Baseline with the pTTT approach using structured behavioral observations, behavioural analysis and environmental scan, e.g.,**
  - Comfort zone exploration? Physical & emotional wellbeing? Affected interactions?
    - Sensory dysfunctions//recognition of pain
    - Physical activities and sports
    - Playing abilities
  - Nutrition
    - Diets
    - Micronutrients
    - Vitamins including iron deficiency
  - Environment
    - Stressors

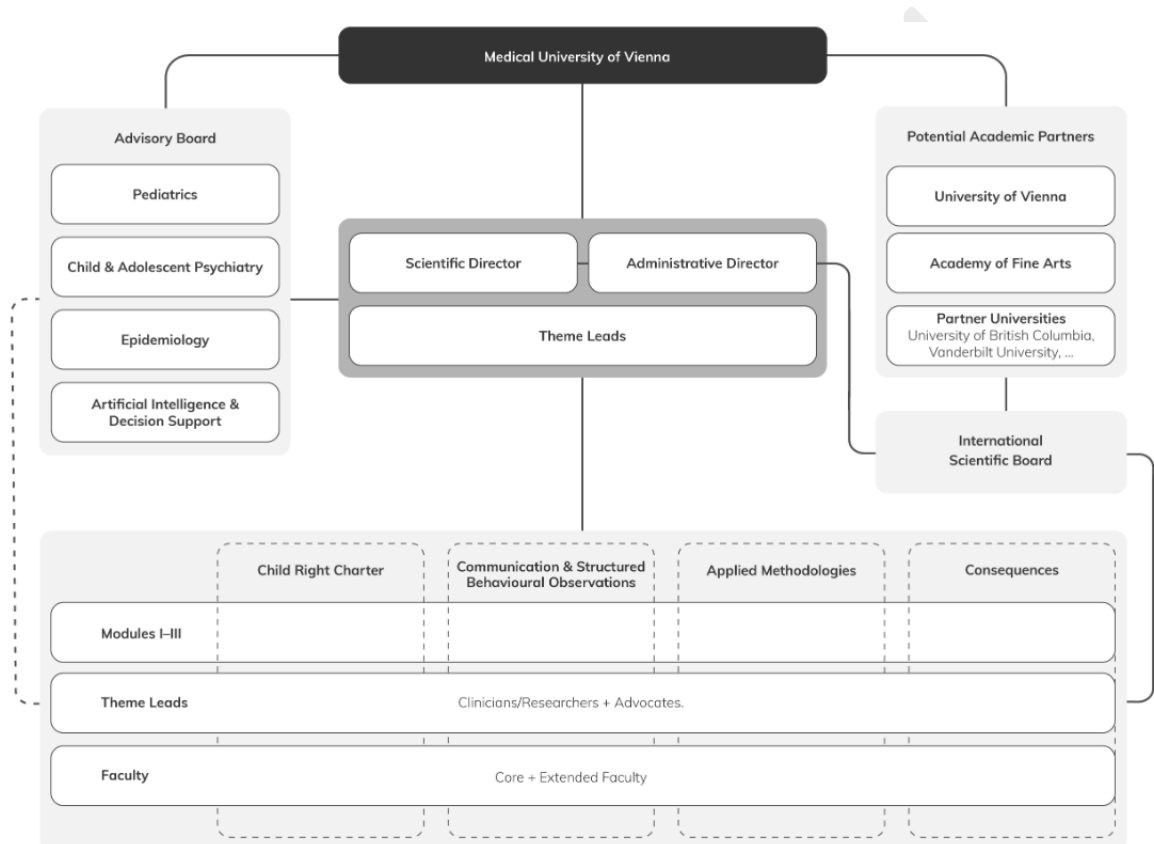
- Family ecology, interactions and dynamics
  - Behaviours in group settings
  - History of applied interventions
    - non-pharmacological
    - pharmaceutical
- III. Interventions & Therapeutic Monitoring: Agreeing on Outcome Measures (to be negotiated & documented) ^ Communication**
- Non-medical interventions
  - Mixture
  - Medical interventions

### pTTT Approach & Interventions



**Figure 5** Overview of Course II. Applying the pTTT Approach. Content regarding disorders and syndromes, their assessment and interventions will be presented utilizing the pTTT methodologies applied in behavioural sciences, allied health professionals and medicine and will be built on social-cultural context, with an introductory and advanced I levels.

Each medical spectrum will be explored from a worst-/best-case scenario perspective (e.g. self-injurious behaviours and upper end of the norm, respectively). Further additional in-depth work packages will be created for syndrome specific knowledge, e.g., Angelman syndrome, Down syndrome, PKU, Rett syndrome, specific biochemical and genetic diseases. These blocks will allow the integration of further international faculty and collaboration partners.



**Figure 6** demonstrates the organogram of the proposed postgraduate courses embedded in the scientific and academic administration of a host university (to be identified; e.g., Medical University of Vienna or Sigmund Freud University, Vienna) and the consulting Advisory Board consisting of the heads of the listed departments and Scientific Advisory Board out of which core and/or extended faculty members can be recruited.

**Scientific Partners.** The modules will be developed with European and International bodies offering certified credits (e.g. European Academy of Childhood Disabilities, Italian Society for Neurology, German Society for Sleep Medicine, Austrian Society for Pediatrics & Adolescent Medicine etc.) for addressing practitioners, who want to learn and apply the knowledge but otherwise might not be interested in attending an entire postgraduate course. This will address a broader group of professionals and enable interested professionals' participation without attending the courses for achieving a Master of Science degree. For receiving a Master of Science degree in total 2000 hours of additional coursework with a research thesis is needed. The advisory board, consists of the Heads of the Departments for Pediatrics, Child & Adolescent Psychiatry, Epidemiology and Institute for Artificial Intelligence & Decision Support, will oversee activities and

curriculum development – this will guarantee harmonization between courses I and II, avoiding redundancies, which may reduce motivation of end-users, interested professionals and advocates and integration of the offered postgraduate course in the academic setting of the Medical University of Vienna.

DRAFT February 2021