

# Developing research in occupational therapy

As the demand for a standardised assessment for occupational therapists grows in German-speaking Europe, **Professor Julie Page** outlines the challenges and the need to raise the profile of OT research in Switzerland

## Can you explain what occupational therapy (OT) is and its importance?

Occupational therapists are concerned with integrating sick or disabled people into the community and promoting their full participation in society. Specifically, the focus of the occupational therapist is to optimise a person's ability to perform the daily life tasks and activities that they want, need or are expected to perform; essentially, helping them with the everyday skills they need to live. For those disabled in some way, activities such as closing a zipper or peeling a carrot can become extremely challenging. Occupational therapists analyse people's capability to perform everyday activities and then support them to adapt to these situations by practicing such activities and, if necessary, by providing assistive devices.

## Why is OT research relatively new in Switzerland?

Firstly, the education of health professions at an academic level in Switzerland has resulted in the need for greater – and culturally relevant – academic research as a basis for academic study. Secondly, the call for outcome-orientated and evidence-based medicine and practice has highlighted the necessity for research. Interventions are now being evaluated concerning their effectiveness and efficacy. This knowledge especially interests health insurance companies who often make decisions about paying for a treatment based on research. We know from experience that OT can support many people with disabilities in various life situations – what we need is more data.

## What is the Paediatric Evaluation of Disability Inventory (PEDI) and how are you adapting it to a German-speaking audience?

The PEDI is an assessment used in clinical practice by various health professionals, such as occupational or physical therapists.

It aims at evaluating the ability to perform activities of daily living such as grooming and getting dressed, moving around in different environments and interacting socially. It was developed for use in the US in 1992 for disabled children aged six months to seven and a half years. The PEDI is conducted by a health professional in the form of an interview with the child's primary caregiver (eg. mother). Based on the result of this assessment an occupational therapist can identify what areas need to be targeted in the patient's therapy.

To adapt the PEDI to a German-speaking audience, a cross-cultural translation and adaptation of the original assessment is done – an extensive process that focuses on both language and cultural adaptation issues. The aim of this is to ensure that the activities of daily living included in the assessment are of importance in the target culture. The next step includes evaluating the psychometrics of the translated assessment, which we are currently doing.

## How will this assessment improve the lives of disabled children?

The PEDI identifies any developmental issues children may have, for example disabled children may have difficulties in performing activities such as tooth brushing or tying shoelaces. After the initial assessment, to evaluate the effect of an OT intervention the therapist can use the PEDI to measure the child's ability to perform certain activities after intervention and compare the result with the assessment before intervention.



(Left to right): Christina Schulze, PhD student; Professor Julie Page, lead researcher; Anders Kottorp, supervisor to Schulze.

## Has the fact that OT research is in its infancy in Switzerland posed any challenges?

Our small professional group of less than 3,000 occupational therapists in Switzerland (compared to about 10,000 physical therapists) needs to cooperate with the European OT scientific community to develop research and possibilities for further scientific qualification beyond a Bachelor's degree. Three members of our research group are pursuing their PhD at universities abroad as they cannot earn a PhD in OT in Switzerland. Christina Schulze, for example, is writing her PhD thesis on the abovementioned PEDI project at the Karolinska Institutet in Stockholm. Anders Kottorp is her main PhD supervisor in Stockholm and a close collaborator for us in joint research projects.

## What does the future hold for OT research?

Developing a new research area is an exciting and challenging task. So far, not enough research has been done in this area. This kind of research is therefore quite new and it is important that strategic funding is available to us. As in all research we perform a balancing act between the needs and expectations of different stakeholders – ultimately our goal in research is to provide new knowledge that will support people with different types of limitations to manage their everyday activities so they can participate in our society and community as well as others.



regardless of assessor. Since 1992, occupational therapists in the US have used the Paediatric Evaluation of Disability Inventory (PEDI), as a basis for assessment of children in the nation – and so have many other countries across the world. The assessment, which takes around 30–40 minutes to complete and can be undertaken by a parent, carer or occupational therapist, provides clinical experts with a rating for various everyday activities based on observed performance, the level of caregiver assistance required and any modifications demanded by the child. These scores are then used to target any health interventions necessary to improve the health, wellbeing and quality of life of the child in question.

Currently the PEDI does not exist in the German language, meaning reliable assessments of disabled children across German speaking countries are potentially difficult and erratic. In response to demands from the German-speaking health academic community – as well as the more pernicious pressure exerted by health insurance companies who are called upon to pay for therapies and treatments – researchers in Switzerland, using the US version of the PEDI as their basis, are seeking to adapt the assessment to a German audience. To make it relevant the team, led by Professor Julie Page, must translate not only the PEDI content, but also the culture captured in the test from American to German to make it an effective tool suitable for children from German-speaking countries – a task posing many challenges.

#### MORE THAN WORDS

The first phase of the project – which began in 2009 – involved the translation of the PEDI from

## Standardising OT tools

A team at the School of Health Professions at the **Zurich University of Applied Sciences** is helping German-speaking occupational therapists by creating a new and culturally-relevant tool to assess disabled children's ability to perform everyday activities

**DO CHILDREN FROM** Switzerland or Germany perform activities of daily living such as tying their shoelaces differently to children in the US? Do they use both hands for eating or only one? Do they prefer to shower or do they bathe? These may seem like odd questions but for researchers in Zurich exploring the new area of research in occupational therapy (OT), they are fundamental issues that need to be understood in order to produce a culturally-relevant standardised tool for assessing the development of disabled children. OT, which aims to enable disabled

or sick individuals to perform meaningful and purposeful activities, is an under-researched area in the German-speaking part of Europe and more data are being demanded by Austria, Germany and Switzerland's new generation of occupational therapists.

When assessing the development of disabled children occupational therapists use standardised forms and metrics to ensure consistency and clarity in the process, with the aim that every evaluation will produce the same results,

## INTELLIGENCE

### ADAPTATION OF THE PAEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI) TO THE GERMAN-SPEAKING AREA IN EUROPE AND VALIDATION OF THE GERMAN VERSION

#### OBJECTIVES

- To provide health professionals working with children with an assessment able to evaluate the performance of activities of daily living
- To translate the PEDI from English to German; adapt its contents to the German-speaking culture; and test for reliability and validity of the adapted version for use in Austria, Switzerland and Germany

#### KEY COLLABORATORS

Children's Hospital of Eastern Switzerland; Ostschweizer Kinderspital St Galle, Switzerland • University Hospital of Würzburg; Centre for Early Diagnosis (Frühdiagnosezentrum/ Sozialpädiatrisches Zentrum); Heinrich Piepmeyer Haus in Münster; Rehabilitation Centre for Children With Special Needs, Germany • Universitätsklinik für Kinder- und Jugendchirurgie; Department of Pediatric and Adolescent Surgery – Medical University of Graz, Austria

Various other therapists in Austria, Germany and Switzerland

#### FUNDING

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**JULIE PAGE** holds a Phd in Sociology of Health from the University of Zurich. As Head of R&D in occupational therapy she started developing her research group, which currently has seven members, at the Zurich University of Applied Sciences in 2007. She became Professor of Evaluation and Assessments in occupational therapy in June 2011. Currently, she is President of the Research Committee of Sociology of Health for the Swiss Association of Sociology.

its English form to German by two translators – one a clinical expert and the other a native German speaker – working independently of one another, to create two translations of the assessment. These were analysed and amalgamated to produce a synthesis of the two, creating a text both clinically reliable but also readable and understandable for parents as well as clinicians.

Once completed, a multidisciplinary review committee comprising paediatric rehabilitation specialists, a developmental psychologist and a translator – as well as a moderator – was convened to assess the similarities and differences of the texts (original and translation) and compromise on a first draft of the German assessment.

In understanding the challenges posed by the translation process, the phrase 'cultural adaptation' is often used. Essentially, when translating the assessment, the nature of the activities undertaken – tying a shoelace, washing and cleaning or eating a meal for example – need to be understood within a child's particular culture to be relevant and ensure an accurate judgement. Performing daily activities is influenced by culture, personal beliefs and context, and children in different cultures learn skills in different ways and at different times. For instance, functional skills may develop earlier or later in German-speaking children compared to their US equivalents – so researchers must understand where development activities fit within that culture to develop a realistic and reliable framework for assessment. "The activities of daily living included in the assessment need to be of key importance in the target culture," explains Page.

Furthermore, Austria, Germany and Switzerland – all German speaking countries – use words differently and differ slightly in their culture; therefore representatives from the different countries are included in the adaptation process as well as during the data collection. If these cultural issues are ignored or a culturally-insensitive assessment methodology is used, occupational therapists may receive an inaccurate or misleading assessment of a child's development – leading to wasted treatment time, resources and potentially resulting in more challenging issues affecting the child in the future.

#### APPLIANCE OF SCIENCE

The project, currently on track to produce a German language PEDI in 2014, has so far fulfilled the adaptation step resulting in a fluent and

culturally-sensitive working document ready for researchers to move on to the next stage – a rigorous testing process. The team is currently testing the psychometrics to develop and refine the assessment. This involves for example, an assessor meeting a child and completing an assessment whilst being filmed. The scores are kept secret; a second analysis is performed by a different assessor using the captured film footage and the resulting scores are compared.

Ultimately, the aim is to create a PEDI that delivers the same results time-after-time, regardless of assessor, that can assess a child's restrictions in activities of daily living and is sensitive enough to point therapists as to where to start their treatment. "By testing the psychometric properties, we want to know whether the translated PEDI measures what we want it to, namely the activities of daily living, in a reliable way in its new context," Page adds. Once the psychometric testing has been completed, researchers will undertake a process to develop the normative values of the PEDI, its final stage before approval.

The group hopes that the translation of the PEDI into German will raise the standards of assessment for disabled children and, as a result, the standards of treatment for disabled children in Austria, Germany and Switzerland. This is something Page and the team recognise: "Ultimately the goal of our research is to provide knowledge that will support people to manage their everyday activities so they can better participate in our society".

#### A NEW AREA OF RESEARCH

Compared to practitioners operating in the US, UK and Scandinavia, occupational therapists in Austria, Germany and Switzerland currently have limited access to culturally relevant specialist research – but this is changing. It is hoped that this project – amongst others conducted at the School of Health Professions in Zurich in cooperation with a wide range of German-speaking partners and professionals across central Europe – will provide an added impetus to an area of study becoming more important every year.

However, this is not an easy task. "Developing a new research area is a balancing act between the needs and expectations of different stakeholders: occupational therapists, health insurers and the funding bodies," Page comments, acknowledging a situation familiar to researchers across the globe.

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