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Typology of Coordinating Complex Health Care Needs of People with PIMD: An International Comparison

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Four Different Coordinating Structures Dealing with PIMD'S Complex Health Care Needs

Coordinating Structures	Country	Key-person coordinating complex health care needs of PIMD (M.A.)								
		Parents	Social Worker	Pediatrician	GP	ID Physician	Nurse	Home Caregiver	Daycare Staff	Others
I Parents + SW	Canada									
II Parents + SW + Medical Staff	England									
	Sweden									
	Switzerland									
III Care Staff in facilities	Belgium									Caregiver in Institution
	Netherlands									Healthcare Psychologist
IV Parents + Medical Staff	Germany									
	Italy									
	Japan									

Introduction

People with PIMD have very severe cognitive, neuromotor, and sensory disabilities, which lead to complex health care support needs. Therefore their community living involves care coordination, the combination of different professionals, and the delivery of individually appropriate services. The importance of care coordinators engaging with people with PIMD gained international and universal recognition through the 7th SIRG-PIMD roundtable meeting in Sweden (2015) and the roundtable meeting of the World Congress in Melbourne (2016).

Objective

This study focuses on the international comparison of coordination of complex health care needs of people with PIMD, and examines which individuals play the coordinating role of complex health care needs in each country.

Method

Data was gathered by a questionnaire distributed at the 7th SIRG-PIMD Roundtable Meeting in Sweden (2015). The questionnaire asked which individuals play the coordinating role in providing health care needs for individuals with PIMD. Respondents were given nine response options: Parents, Social Workers (SW), Pediatricians, GPs, ID physicians, Nurses, Home Caregivers, Daycare Staff, Other. One researcher from all nine participating countries responded to the question.

Results

First, parents have the role of coordinating in all eight countries, except for The Netherlands. Following this, pediatricians play a major role of coordinating in five countries, and SWs play a coordinating role in less than half of the countries. These findings show that there are four different coordinating structures for dealing with PIMD's complex health care needs throughout the countries surveyed:

- I Parents + SW (Canada)**
- II Parents + SW + Medical Staff (England, Sweden, Switzerland)**
- III Care Staff in facilities (Belgium, The Netherlands)**
- IV Parents + Medical Staff (Germany, Italy, Japan)**

Discussion

The differences between the four types of structures suggest that there is a difference in social status of professionals engaging in PIMD community living support in each country.

In Canada (Type I) SWs play an important role. By contrast, in Germany, Italy, and Japan (Type IV) Medical staff assumes a key role for coordinating PIMD care needs. Yet, in Belgium and The Netherlands (Type III), care staff in facilities which are involved in PIMD community living is the main coordinator.

In making a training curriculum for coordinators engaging with PIMD health care needs, different methods in accordance with different professions or disciplines are necessary, based on these four types of structures. It is suggested that countries with similar coordination structures, strengthen their cooperation in addressing PIMD needs.