

# Global semantic interoperability a tool to ensure full participation in society.

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## Introduction

Individuals with a disability are particularly vulnerable to deficiencies in health care services. Due to lack of accessible diagnostic tests rare conditions are heavily under diagnosed. Once diagnosed social support is denied or inappropriate. Affected, caretakers are becoming experts. They spend a lot of time searching for supporting tools & finances. Providing quality information enables full participation in society.

How can international classifications help individuals, and others to describe the impact of a rare condition on daily life?

## Methods:

Rare conditions are complex. One gene defect usually affects more than one body function. So rare condition(s) are composed as a combination of sometimes (not so rare) diseases. Each disease can be coded with the International Classification of Disease (ICD).

The International Classification of Function (ICF) establishes a level of possible activities and participation. The disease – ICF combination forms a module applicable to different rare conditions.

For example: an intellectual disability occurs relatively common in (rare) conditions. People with Shwachman Diamond Syndrome as well as people with neurofibromatosis, may have a mild intellectual disability. The level of function deficit can be graded with the ICF. Young adults want to get their driver's license. To get the license it costs extra effort and budget. The ICF can grade the level of difficulties, with and without aid.

Both ICF as well as ICD are global interoperable standards. The ICD – ICF modules can give insight in actual participation of individuals and how to optimize their life changes.

## Results:

The combination of disease- and function classifications can help individuals with a rare condition to give the insight in the possibilities and objectivize their demands for assistant tools.

Conclusion: The use of interoperable terminologies is the opportunity to harmonize care of individuals with a rare condition.

[www.rarecare.world](http://www.rarecare.world)

