

Rare Navigators helps PLWRD manage

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Introduction

Rare Diseases Denmark currently conducts a project (2015-2017) granted by the Danish Health Authority to educate and employ Volunteer Rare Navigators. The goal is to equalize disparities and promote health and health literacy in the most vulnerable PLWRDs in the Danish healthcare system.

Navigators draw on personal and -professional skills

A Navigator is a person that based on experience-based knowledge provides personal guidance to vulnerable PLWRD navigating the Danish health care system and accessing the social system. Navigators are either suffering from a rare disease themselves or a relative of a PLWRD.



"Being a Navigator is like being the captain on a container ship. It requires overview and navigation skills in high seas and calm waters to help PLWRD through, without them getting seasick. I could have used support from a navigator when my children and husband got diagnosed with tuberous sclerosis. Based on my experience I want to make that difference for another family"

Tells Karina who is one of Rare Diseases Denmark's 18 navigators.

The task

Providing coordination between and within the systems is a task for social- and health care professionals. However, Rare Diseases Denmark is prepared to contribute to improve the conditions for PLWRD through voluntary action and participate in the important effort to support PLWRDs in the process of:

- Acknowledging personal situation
- Creating an overview of options
- Encouraging health literacy and support compliance

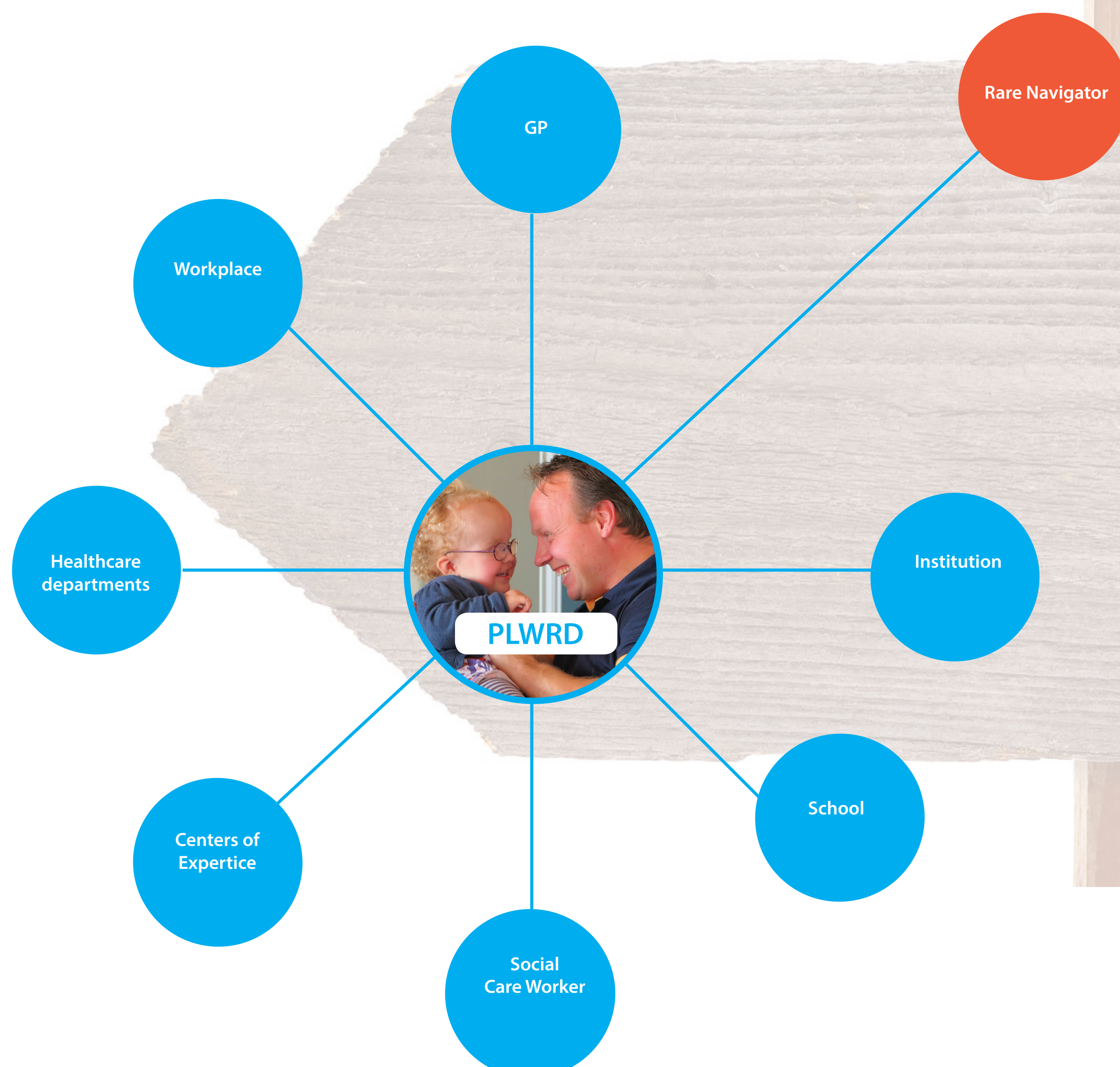
Navigators support and empower the wishes, priorities and decisions of vulnerable PLWRD through the principle of helping them to help themselves. Rare Navigators can help ensure that patients don't fall through the cracks so they can follow their treatment plans and improve their health literacy. In addition to the personal knowledge Navigators, Rare Diseases Denmark provides an education and continuously support program for the Navigators.

Evaluation

To study the impact of receiving support from a Navigator, all the PLWRDs involved in the project, answer the WHO-Five Well-being Index questionnaire in the beginning and in the end of an navigation. The results will be presented to the Danish Health Authorities in order to document PLWRD continued need for help navigating the systems.

Facts

Originally the Patient Navigation concept was developed in the US to improve outcome in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases. Rare Diseases Denmark has made it probable that PLWRD's is particularly vulnerable in the healthcare system because of the complexity and rareness of the illness. Standard procedures do not work for these patients and they need help navigating the systems.



"I support a woman with an ultra-rare disease. She has lost confidence in the social- and health-care systems. She no longer dares to ask for the social support and the treatments she needs to live a good life. As a patient myself and a social worker I am supporting her to take responsibility for her own life. She is so brave and is slowly gaining back confidence"

Tells Rune who is one of Rare Diseases Denmark's 18 navigators.

Navigators play a role, in the lives of the PLWRD, for maximum 12 months. The navigation depends entirely on the individual's needs and the complexity.



Rare Diseases Denmark

Rare Diseases Denmark

- Rare Diseases Denmark is a national alliance of 52 small rare disease societies. The societies are mainly run through voluntary work by patients and their relatives. Rare Diseases Denmark also hosts NURD – Network for patients and relatives affected by Ultra Rare Diseases.
- The work of Rare Diseases Denmark is based on volunteers and a minor professional secretariat.
- Rare Diseases Denmark has an ambition to work for all rare citizens, also those without a patient network or society.
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