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Poster Abstract

Does an individual plan make better services for children with rare disorders?

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Abstract

Background: TRS National Resource Centre for Rare Disorders offers services to seven diagnostic groups of rare congenital disorders, mainly related to the skeletal- and muscular system. The centre works to increase knowledge and offer guidance and counselling on medical, psychological, social and educational issues relating to the diagnostic groups. The centre has a multidisciplinary staff and is a part of the Sunnaas Rehabilitation Hospital, located just outside Oslo, Norway.

TRS is a supplement to the ordinary service providers and promotes cooperation between users, staff members and representatives at all levels of the Norwegian public services. TRS produces information materials and articles about the diagnostic groups and has an internal research program. The presenter has been working as a social worker at TRS since 1996.

Purpose: Many families who have children with rare disorders have a complex follow-up regime that involves school, social and health related services both locally and on the centralized level. The parents often spend a lot of time and energy on organizing the support system. In Norway individual plan (IP) is the main tool intended to help people with complex conditions organizing their support system. We wanted to investigate whether individual plan was used, and by whom. We also wanted to find out if the parents were satisfied with the services they received and if they participated in establishing the services.

Methods: Cross-sectional study. A questionnaire was sent to parents of 439 schoolchildren (6-18 years) with congenital rare disorders registered in a database at TRS National Resource Center for Rare Disorders. A combination of standardized tools and self composed questions were used. Results: Response rate 48% (N=209). Average age 12 years, 50% were girls. 43% of the children had IP. The higher number of services, the more likely they were to have IP. Most parents reported a high level of satisfaction with received services and also a high level of participation in establishing the services. Whether they had IP or not, did not influence on satisfaction and participation. The parents experienced that IP led to better cooperation between the professionals, but IP did in a much lesser degree ease their burden of coordinating the services.

Conclusion: Most parents were satisfied with the services they received and the participation in the development of these. The level of satisfaction and participation were not affected by whether they had IP or not. IP showed good effect in many areas, but did in lesser degree relieve the

burden of coordination. It therefore appears as if IP had a positive impact in other areas than where it was originally intended.

Whether there is a need for new measures to relieve parents from the strains of coordination and follow-up, or if the focus should be shifted to establish schemes supporting parents in carrying out this work themselves should be further examined.

These results are preliminary and the findings have not yet been published.

Keywords

individual plan; rare congenital disorders; coordination; satisfaction with services; participation

PowerPoint presentation

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