

# EMPOWERMENT INTERVENTION for persons affected by Williams Syndrome: a pilot project at the Bambino Gesù Children's Hospital

De Lorenzo F\*, Macchiaiolo M., Buonuomo P.S., Capolino R.,  
Dentici M.L., Digilio M.C., Bartuli A.



## SUMMARY OF PURPOSE

The Bambino Gesù Children's Hospital Research Institute (Rare and Genetic Diseases Unit) has designed, implemented and evaluated an Empowerment Intervention and best practice to ensure inclusion of persons living with a rare disease: Williams Syndrome.

Williams Syndrome is characterized by a combination of distinguishing physical traits, congenital anomalies, intellectual disabilities, and a specific developmental profile.

Few scientific studies address interventions aimed to improve quality of life of adult Williams Syndrome individuals.

## METHODOLOGY

Our Williams Syndrome patients ages 25-30 have adequate cognitive, cultural and social skills.

Workplace is located in the Hospital Playroom and the Administration office of the Department of Rare Diseases. Activity plan was devised into steps and with specific goals, taking into consideration the peaks and valleys of Williams Syndrome and the specific personality of our patients.



## OBJECTIVES

- ❑ To develop patient's self awareness of their internal and external resources to effectively use them and increase self-efficacy;
- ❑ To plan work activities to guide and facilitate work environment improving patient self-management skills;
- ❑ Supporting patient to improve their quality of life, to live as independently as possible and to develop their ability to self-care.

## CONCLUSIONS

This project represents a pilot and unique experience in Italy; it also wants to serve as a reference model to encourage healthcare institutions and social policies to dedicate more attention to the psychological and social wellbeing of patients affected by rare conditions.



## NEXT STEP

- ❑ To devise educational programs to develop skills of personal and social self-sufficiency from a very young age;
- ❑ To devise gradual and targeted interventions to facilitate their entry into the labour market.

*Just like anyone else, Williams Syndrome patients want to establish emotional attachments and be perceived as adults and to make a living.*



*Everyone has the right to be a person beyond their illness, to have a role in the society, to belong to a community that is not only that of their own syndrome, To make choices, to create stable extrafamily ties, to feel useful to others and sufficient for themselves.*

THAT'S THE CHALLENGE OF OUR PROJECT!