

## CONFERENCE ABSTRACT

# Enhanced family-centered care coordination for children with special needs in the Basque Region

16<sup>th</sup> International Conference on Integrated Care, Barcelona 23-25 May 2016

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Pediatric care coordination is a patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children with special healthcare needs (CHSCN) while enhancing the care-giving capabilities of families. CHSCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Effective, coordinated care amongst all of the professionals implicated in the care of these children, provided during the first several years of their life, has been correlated improved outcomes for CHSCN and their families.

At the center of care coordination are the families and children involved. Effective care coordination with families results in improved coordination and health outcomes, increased satisfaction by all involved, decreased barriers, and fewer unmet needs.

Following the model of early intervention adapted in the Basque Region in 2011, with a focus on early intervention for children 0-6 years old, and care coordination between the health, social, and educational services, the model of integrated care for children with special needs, PAINNE (Proceso de Atención Integrada a Niños y Niñas con Necesidades Especiales) was created in 2012.

The overall aim of this project is to implement an integrated model of care for CHSCN, ages 0-6 years, using a quality improvement method to enhance the overall care and satisfaction of the children and families affected. This model was initially implemented in Bilbao, and more recently in the entire province of Vizcaya. This model promotes quality care for children and their families in a way that is efficient and sustainable, with the goal of early detection and intervention in situations of risk, ultimately aiming to help these children reach their maximum potential and improve their overall quality of life.

In the second phase of this project, with its expansion into Vizcaya, in accordance the quality improvement methodology, it was determined that this model should move to more actively include families. Three specific activities were incorporated into this model to enhance the family-centered approach:

1. Sub-processes to address the integrative needs of specific groups of CHSCN are being organized. These sub-processes are centered on the necessities of the children and their families, focusing the areas of improvement and barriers to care that they and other providers identify. The work groups consist of parents of affected children; representatives from the third sector, pediatric primary care teams, and special education; other professionals in the healthcare, social services, or education sectors that care for these children; and the coordinating team from PAINNE. The objectives are to reach consensus regarding best practices for family-centered integrated care for children affected by a specific process, publish the document as part of the revised PAINNE guide, and disseminate this approach to professionals the three sectors and third sector. Several sub-processes have been initiated in Vizcaya, intending to provide a more integrated, family-centered approach to children that are severely hearing impaired, with Down Syndrome, Cerebral Palsy, Autism, and others.

2. Families of CSHCN are being recruited to participate in focus groups and help develop instruments to measure families' satisfaction with this new model of integrated care, which is crucial to promote continuous quality improvement. These surveys will be administered to families of CSHCN in Bilbao, then later in Vizcaya.

3. There is greater representation by members of the third sector in all aspects of the process of the expansion of PAINNE to Vizcaya. Over 25 members of the third sector are actively participating in the multidisciplinary work groups formed to validate, adapt, revise and implement the ideas set forth by PAINNE in Bilbao. It was deemed important to form a separate work group with these advocates to better orient all professionals towards enhanced care-coordination and improved quality of life for children and families. This group is creating a document of best practices in the care towards families, including the communication of the diagnosis, family support and advocacy, and orientation for families.

The enhanced family-centered approach to the integrated model of care for young CSHCN in Vizcaya has been a positive experience for professionals in healthcare, social services, education, and the third sector, as well for families. The innovative, family-centered, multidisciplinary, quality-focused methods used in this process will allow for the creation and publication of best practices in the next 1-2 years that should be valid, replicable, and have high-level of consensus not just amongst professionals from distinct organizations, but also with families and their advocates.

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**Keywords:** family-centered care; children with special healthcare needs; care coordination; families; third sector

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