Basque Country: Integrated care process for children with special needs (PAINNE)

Part 1: General Information

Publication on EIP on AHA Portal	Yes
Copyright	No
Verification of the Good Practice	No
Evaluation of the Good Practice	Yes
Type of the Good Practice	Notable practice

Part 2: Description of the Good Practice

Name of the Good Practice	Integrated care process for children with special needs
Short name (Acronym)	PAINNE
URL of the Good Practice	Not available
Geographical scope	Local level
Country	Spain
Region(s) involved	Basque Country
Status of the Good Practice	On-going
Stakeholders involved	• Hospitals • Primary care centres • Specialised physicians • General Practitioners • Nurses • Regional public authorities • Local public authorities • Advocacy organisations • Third sector • Other (Family members)
Size of population covered	10, 000 – 99,999
Targeted audience	< 18

Summary of the Good Practice

The overall aim of this PAINNE (Proceso de Atención Integrada a Niños y Niñas con Necesidades Especiales) is to implement an integrated model of care for children with special healthcare needs (CSHCN), using a quality improvement method to enhance the overall care and satisfaction of the children and families affected. This model promotes quality care towards 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. Multidisciplinary groups comprised of nearly 90 professionals from the healthcare, social services and education sectors in Bilbao worked together to create appropriate structures for care coordination, reach consensus regarding procedures to offer integrated care and tools to enhance early detection of situations of risk, define key indicators for quality improvement, and create a comprehensive directory of resources in these three sectors. These ideas were published in the Guía PAINNE 2013, and the screening tools agreed upon for the early detection of developmental delays and psychosocial risk factors were incorporated into the electronic medical record (EMR) for routine use in well child visits in the paediatric primary care centres in Bilbao. Currently, more than 200 professionals in the healthcare, social services, education and third sectors are revising the guide in order to publish an updated version in 2016 and are implementing the model throughout Vizcaya.

Key words: children with special healthcare needs, care coordination, early intervention, prevention of childhood deficits, health and social care

Good practice being part of the larger programme

No.

Challenges / problems addressed by the good practice

- Detect early the biological, psychological and social family risk factors that may affect the normal development of children.
- Detect early warning signs or any other alterations in the development of a child.
- Establish personalized therapeutic measures which allow children to reach their maximum personal and developmental potential, and achieve educational and social integration.
- Improve the communication amongst the people and organisations involved to enhance the coordination of each case.
- Improve the children and their families' quality of life.

Importance of the challenges / problems before starting to implement good practice

- Early detection of risk factors and early warning signs- although this is a cornerstone of primary care paediatrics, there were no specific screening tools or algorithms in place that would systematically allow for early detection of difficulties during the well child visits.
- Individualized care plans were not always coordinated between the various providers in the different sectors, nor were they centred in the needs of the children and their families at this time either.
- Communication between the three sectors, as well as within each sector, was not optimal.

Environment before the good practice was implemented

In 2011, the Basque government passed an early intervention model that was based on coordination of services between the healthcare, social services, and education sectors and expanded services from 0-3 years to 0-6 years. This facilitated the coordination amongst the three sectors, allowed for the formation of an early intervention structure and provided the pathway for PAINNE to be initiated the following year. In primary care, paediatricians and nurses did generally screen for developmental problems, and provided known resources. However, the developmental screens were not standardized, and the initiative to implement these screens and offer needed resources depended on the professional that the family encountered. The EMR offered visibility between primary care and specialists, with enhanced the coordination of care, but referral pathways were not always clearly defined or understood. Coordination amongst professionals in some local communities was well-established, while in others, scare, with little knowledge of local resources.
Key innovative elements of the good practice and how the good practice improved situation compared to previous practice 1. Definition of activities and indicators for evaluation and continuous quality improvement 2. Consensus regarding tools for the early detection of risk factors and deficiencies 3. Development of protocols and referral pathways to offer an integrated response to CSHCN 4. Implementation of screening tools and alerts in the EMRs, both in primary care and in the hospital 5. Creation of a Directory of Resources including social, healthcare, and educational resources PAINNE is a quality-driven model that has offered enhanced coordinated care for CSHCN, based on the needs of families. The implementation of screening tools to detect early developmental and psychosocial risk factors and standardized referral pathways not only have been well-received by primary care teams, but have shown to decrease referral times for children suspected of having autism spectrum disorders. The early intervention teams accepted the vast majority of children referred by healthcare professionals, allowing for early, individualized care. Communication and referrals between professionals has also been enhanced.

Part 3: Transferability of the Good Practice

Cost-effectiveness of the good practice (including all kind of costs and outcomes such as better health, quality of life or other resources)	Equal costs, improved outcomes

Resources required for the deployment of the good practice (personnel, equipment, facilitie resources required)

This model does not require additional resources, but rather is based on the redistribution of current

This holds true in each of the three sectors. Each of the three sectors has allocated time and reso current structures and budgets for the participation of professionals in multidisciplinary work improvement and ongoing continuing education in order to implement this model.

In the healthcare sector, grant and regional funding did allow for a few professionals to have protecte and oversee the process. Other professionals that participated in the work groups were allocated organisations. Primary care teams incorporated the screening tools into their daily practices, withou or resources needed.

An early intervention team was formed under the umbrella of social services in conjunction with the c model, which facilitated the assessment and preparation of individualized intervention plans. Profe three sectors also participate in assessment and quality control groups, which is part of their profes time.

In education, professionals formed a department for early intervention amongst experienced curre order to better address the needs of young children and implement screening tools in the preschools from the third sector were also allocated time to participate in work groups.
The early structural changes in each sector are now in place in Bilbao and professionals can dedica efforts to quality improvement and enhancing implementation.

Total budget of the Good Practice	€100.00 - €499,999
Source of funding	Regional funding

The main actions that have to be done to deploy the Good Practice

Certain actions taken by the Basque government, such as the approval of an early intervention mod 0-6 years and the formation of an early intervention structure, facilitated the implementation of this professionals from the three sectors formed from five multidisciplinary work groups in order to indicators for quality improvement and evaluation of the process. These work groups also reach appropriate screening tools, protocols, and referral pathways. The coordinated care guide (Guía P directory of resources, and the changes in the EMR in primary care and the hospital were products o Professionals in each of the three sectors were trained and educated about the process and early int initial results were positive and professionals were engaged in Bilbao, the model was expanded to al than 200 professionals from the healthcare, social services, education and third sectors participated revise, validate and adapt the current care guide and prepare the publication of an updated guide in 20 of resources was expanded to include resources from the entire territory. Healthcare organisations Vizcaya have begun implementing the process. Additionally, the third sector formed its own work g have participated more actively in this second phase. Families have participated in focus groups multidisciplinary work groups created to offer an integrated care response to children with specific such as Downs Syndrome, Cerebral Palsy, and Autism.

Issues during the implementation of the Good Practice

Some of the barriers that we have encountered include
1. The complexity of the process and resistance to change
2. Managing the intra- and inter-relationships in the healthcare, social services and education sectors
3. Differences in cultures, language, and procedures in the distinct sectors
4. Lack of new health technologies within and between sectors
5. Lack of time and additional personnel in each sector to more efficiently disseminate and impleme

Additional resources required to scale up Good Practice

No.

Basis to support sustainability of the Good Practice

PAINNE is a bottom-up process that includes practicing professionals from healthcare, social servic sectors as well as advocate groups and families, which has ensured acceptance and quality impr activities with children and families. This model has re-organized existing resources in creative w structural changes, establish referral pathways between professionals, and enhance communicatio ensure long-term, sustainable changes. The model has also been well accepted in in the rest of Vizc be replicable, and its implementation is currently in progress.

Surveys done in Bilbao of primary care paediatricians and nurses have shown that the implement changes is well accepted and perceived as useful. Use of developmental screens routinely in well ch increased from 25% of primary care teams in 2013 to 60% in 2015. Additionally, the Foundation New H evaluator of best practices in Spain, gave this model a score of 4/4 in sustainability.

Evidence to observe the Good Practice

The Guía PAINNE 2013 can be found at:
http://www.osakidetza.euskadi.eus/contenidos/informacion/osk_publicaciones/es_publi/adjuntos/

Publications:
1. Saitua G, Díez C, Aparicio E, Gutiérrez A, Paz C, Floyd M, et al. Proceso de Atención Integrac Necesidades Especiales (PAINNE). Rev Pediatr Aten Primaria [Internet]. 20 http://www.pap.es/FrontOffice/PAP/front/Articulos/Articulo/_IXus5l_LjPq4RQcxodpCfTWUxvkF
2. Aparicio E. Experiencias de atención integrada Pediatría Atención Primaria-Hospital. El pediatra Bol S Vasco-Nav Pediatr. 2014;46:27-32. http://www.svnp.es/sites/default/files/experiencias_en

Additional publications with be available in late 2016, early 2017
External evaluations:
New Health Foundation/ Observatorio de Modelos Integrados en Salud. Available at
http://omis.newhealthfoundation.org/proceso-de-atencion-integrada-a-ninos-y-ninas-con-necesidad painne-2/

Part 4: Viability assessment of the Good Practice

Time needed to deploy the Good Practice

Between one year and three years.

During the first 12-18 months, nearly 90 healthcare, social services and education professionals formed five different work groups. These works groups met various times and using the process management methodology, agreed upon 11 groups of activities, 7 referral pathways and several clinical decision-making tools, a directory of resources, and indicators for continuous quality improvement, which were included and published in the clinical guide. Educational sessions were held in each of the sectors and implementation began in Bilbao after the initial planning phase. The electronic medical system was changed to incorporate these decision- making tools, both in primary care and in the hospital, and providers were trained in their use. Approximately two years after this initial phase in Bilbao began, nearly 200 professionals from these three sectors and the third sector, within the larger territory of Vizcaya, formed four work groups in order to revise and validate the clinical guide. The directory of resources was expanded to include resources from the entire territory. About 18 months' year later, this revised guide will be completed, and implementation of the changes in the medical record and educational sessions are beginning in different regions of this territory. Simultaneously with this model ▫s expansion, families in conjunction with professionals from the healthcare, social services, educational fields and the third sector have formed work groups in order to identify and determine best practices in coordinated care for children with specific healthcare needs or risks. These sub processes include children with Downs Syndrome, Paralysis Cerebral, Autism, Extreme prematurity, and Childhood deafness. The focus is family-centred, with determination of the family ▫s needs and inclusion of families in all aspects of this process.

Investment per citizens / patient / client in terms of financial resources

No available calculation.

It is difficult to calculate the exact cost of this model. Initial funding through a social healthcare grant and ongoing small grants from the healthcare system have covered the cost of a few part-time healthcare professionals to organize the project, write and publish the clinical guide, oversee the project ▫s implementation and promote its expansion. However, though initial funding did provide the impetus to start the project, its success is based on the restructuring of existing resources, not just in the healthcare field, but in the social services and educational areas as well. Multiple healthcare professionals have played a role in the first and second phases of this project, and the changes implemented are now routine parts of primary care. In social services, the onset of this project coincided with the formation of an early intervention team and centre, which now has its own budget to provide early intervention services. Education created an early intervention department from existing personnel, and various professionals in early childhood education are involved in this work. Though we cannot calculate the exact cost of this restructuring, we are certain

that there is cost- savings in each of the areas. Economists, such as Heckman, have shown that early intervention has a notable return on investment throughout the life of the child. Coordinated care also decreases duplications of services, makes more efficient use of the services provided, and minimizes the time spent by the family doing unnecessary transactions and visits. http://heckmanequation.org/heckman-equation

Evidence behind the Good Practice

Documented evidence. Evidence is based on systematic qualitative and quantitative studies.

From the onset of this project, continuous quality improvement has been a key part of the process. The initial work groups developed a set of indicators that have been measured annually since the implementation of the model in 2013 in Bilbao. These indicators were reviewed and revised during the expansion to Vizcaya. Qualitative and quantitative data has been collected from electronic medical records, satisfaction surveys completed by professionals, and databases from the healthcare, social services, and educational systems. Additionally, family satisfaction was of the initial quality indicators. Focus groups were formed to determine the needs of families, the input of families was analysed, and we are currently creating an evaluation based on the input from families, which will be piloted and applied to the affected population in Vizcaya. Lastly, we were evaluated positively by two external sources. One was the social healthcare organisation that initially funded this project, Etorbizi. The other was New Health Foundation, in an observatory for best practices in integrated health in Spain, which can be found at:
http://omis.newhealthfoundation.org/proceso-de- atencion-integrada-a-ninos-y-ninas-con-necesidades-especiales-painne/

Maturity of the Good Practice

There is evidence that the practice is economically viable and brings benefits to the target group. Further research and development is needed in order to achieve market impact and for the practice to become routine use.

As mentioned previously, this model has allowed for restructuring not only in the healthcare field, but also in social services and education. Initial start-up costs have been covered and the changes made are long- lasting. Recent legislature for early intervention promotes integrated care amongst the three sectors in the entire Basque region. The coordinated care model in Bilbao and Vizcaya has helped demonstrate effectiveness, to the point that the legislature deemed it important to expand this model to the entire region. In healthcare, both paediatricians and nurses in primary care evaluated the utility in practice and the perception of improvement positively, and more than half of the providers in different urban areas in the territory attended trainings related to this topic. Data shows that primary care providers are using the new tools more consistently to detect developmental delays and psychosocial problems, and this has had a positive impact on the

age of referral for children with suspected autism. The perception of providers is that communication is improved and referral pathways are clearer. In the expansion of this model to Vizcaya, professionals find the model to be comprehensive and valuable, and have begun implementing the necessary changes in the electronic medical record, even on a personal level when systematic changes have not yet been put in place. The updated clinical guide will be published in early 2017, with revisions that make it applicable to the larger territory of Vizcaya. This guide is an important tool for the promotion and expansion of this model. Families and patient associations have expressed interest and enthusiasm for this model and have been involved at different levels in its preparation and expansion. Family satisfaction questionnaires will provide further insight to the family perception of the impact of this model, and can be validated in different regions.

Estimated time of impact of the Good Practice

Long term and sustainable impact – e.g. a long time after the pilot project ended and routine day-to-day operation began

Impact observed

Better care coordination (economic and societal).

As mentioned previously, qualitative and quantitative data has been collected to determine the impact of this model. Care coordination/ integration has been enhanced quantitatively between paediatrics and social services, with 93-95% of referrals being accepted for early intervention services. Additionally, the age of referral for autism from paediatrics to mental health has decreased from 3.8 years to 3 years with the incorporation of systematic use of assessment tools for development in primary care. Primary care teams are better identifying families with psychosocial risk factors, during prenatal, newborn and well-child visits, which allows greater coordination between primary care and social services and/ or mental health, and the earlier provision of services. Much data supports the effects of early intervention, with an increase of return of investment, better quality of life for children and families, better integration into all aspects of society, and decreased need for specialty and additional services in the healthcare, social services and educational sectors. Qualitative data from surveys and informal interviews with professionals from the three sectors and third sector shows that this model has had a positive impact, is well accepted, is viewed as useful, and all providers note enhanced communication and coordination amongst the sectors. Focus groups with families have also shown positive perceptions of care with enhanced coordination, and family survey questionnaires that are currently being developed will provide greater insight into the direct impact on families.

Transferability of the Good Practice

Ready for transfer, but the innovative practice has not been transferred yet. The innovative practice has been developed on local/regional/national level and transferability has been considered and structural, political and systematic recommendations have been presented. However, the innovative practice has not been transferred yet.

This model has been implemented in Bilbao, and is currently in the implementation phase in the rest of the territory of Vizcaya. The clinical guide published in 2013 compiles best practices from the scientific literature with tools and referral pathways agreed upon by local professionals from the three sectors. With the expansion of this model to the territorial level, the guide has been adapted and enhanced. This guide could be replicated in other regions in the Basque region fairly easily, as the tools and pathways are have been validated and translated to the regional language. On a larger scale, the guide could serve as a model for other regions in both Spain and elsewhere: each region could adapt the tools, referral pathways, and indicators to their needs. The changes implemented in the electronic medical record can also be achieved with buy-in from healthcare organisations and primary care providers. Currently, 2/4 healthcare organisations in Vizcaya have incorporated the recommended tools, and the other two organisations are awaiting structural informatics changes to include these tools. In the education sector, this model has already been adapted at the regional level, throughout all of the Basque region, as their structure is regional. In the social services sector, in conjunction with a recent regulation in early intervention for the Basque region, changes are also being made throughout the region to ensure a social-healthcare-educational model of care.

Part 5: Your organisation

Name of the organisation	OSI Bilbao-Basurto
Address of the organisation	Avenida de Montevideo, 18 - 48013 Bilbao
Type of organisation	Integrated Care Organisation
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