

Addressing the needs of children with rare diseases in education in Northern Ireland

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Contents

- Statistics / overview : Impact of rare diseases for children in education in Northern Ireland
- Literature Reviews
- Parent testimonies – endorsements, challenges and recommendations.
- Addressing needs of teaching / support staff
- The way forward.

Key numbers

9

Definition : A rare disease affects no more than 1 person in 2000

Known disorders : 6,000- 8,000 worldwide

Europe : 30 million individuals

UK : Over 3.7 million individuals

Northern Ireland : Over 110,000 individuals

50% under age 19

70% of rare diseases start in childhood

Only 5% of conditions have a treatment

On average, 5 years to diagnosis

Impact for children



Delayed diagnosis

Multisystemic disorders

Comorbidities

Developmental delay

Physical disabilities

Emotional and social development

Cognitive impact – multifactorial

Medical interventions and hospitalisation

Frequent school absences – sometimes prolonged

Family impact

Impact for learning



Sleep problems /
fatigue

Concentration
difficulties

Distractibility

Listening skills

Social skills

Motor skills
affected

- gross and fine motor delay
- physical agility, balance,
and coordination

Digestive issues
Continence issues
Discomfort

Sensory
challenges

Low self-esteem
and confidence

Lower
expectations and
achievements at
key points

Impact for learning environments



Facilitating reasonable adjustments in physical environment

Understanding needs and relevant adjustments (whole staff)

Need for condition specific training

Links to relevant organisations where available
(e.g. Muscular Dystrophy, Spina Bifida / Hydrocephalus)

Access to rare disease Toolkits

Critical care response (e.g Shunt blockage)

Literature Reviews - common themes



Need for rare disease information and training for improved outcomes for children.

Lack of knowledge to enable school personnel to provide appropriate learning environments and make curricular adjustments.

Children with rare diseases are educationally at risk of failing to achieve expected standards.

Creating optimal educational settings for children with rare diseases – a working method

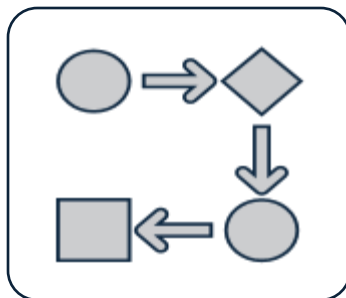
AnnCatrin Röjvika , Gunilla Jaegera ,
Erland Hjelmquistb and Kerstin W.
Falkmanb



Children with rare diseases often **display special education needs** and require **support** and **adapted pedagogical methods** to participate and achieve academic goals.



The results show that rare diseases often have educational consequences and that a **holistic educational method**, applicable to most rare diseases, is needed, but **lacking**.



To contribute to a high-quality inclusive education teachers must **understand how the origin of needs**, including medical facts, their **consequences** and appropriate **adjustments** are **closely linked**.

Inclusion and equity in educational services for children with rare diseases: Challenges and opportunities

Sebastià Vergera, Francisca Negrea ,
Maria Rosa Rossellóa, Berta Paz-
Louridoa

A given rare disease affects a minority of school-aged children, but the provision of **appropriate education** and care is a complex process influenced by:



- the health condition of the individual child,
- the level of empowerment of families,
- the availability of resources
- the commitment of the school and health care providers.



The delay or lack of a clear diagnosis is among the challenges to obtaining the adaptations required.



This highlights **the need for a strategic plan** to address the children's, families' and teaching staff's needs as well as regulate and institutionalize practices in the school.

Rare Diseases in the Educational Field: Knowledge and Perceptions of Spanish Teachers

Ramón García-Perales , Ascensión Palomares-Ruiz , Lydia Ordóñez-García and Eduardo García-Toledano



By completing the questionnaire, the teachers were more aware that their **knowledge and training was insufficient** for providing a proper educational response to the potential and characteristics of these students.



Expanding training processes will be essential in overcoming this pattern. Currently, updating knowledge through continual training has become indispensable.



Education systems must strive to overcome the discrimination in educational processes.

It is clear from this study that there is still a long way to go in providing a proper educational response to these students with rare diseases.

We should be asking ourselves whether schools are doing all they can to offer quality, inclusive education to these students



Testimonies

Participants included families of patients affected by various medical conditions:

- 22q 11 deletion (DiGeorge Syndrome)
- PKU (Phenylketonuria)
- Ehlers-Danlos Syndrome
- Chiari Malformation / Hydrocephalus/ Spina Bifida (Complex)
- EPP (Erythropoietic protoporhria)
- Vacterl Syndrome
- Foetal Valporate Syndrome

(Shared with consent from participants)

Questionnaire



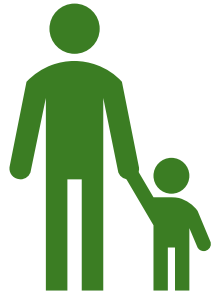
Your Child's condition/s : _____

Age : _____

- 1.** Can you describe an example/s of good practice with regards to your child's needs in school setting? What made the difference?
- 2.** Can you describe an example/s of poor practice in the school setting and explain what happened and any consequences from this?
- 3.** Please add any further comments/advice in relation to training needs for school staff supporting a child with the same condition.
- 4.** Further comments.

1. Can you describe an example/s of good practice with regards to your child's needs in school setting? What made the difference?

Timely Statutory Assessment following diagnosis – child in Year 10 almost expelled due to behavioural challenges

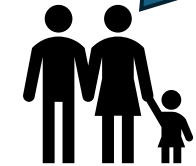


Relevant recommendations by SENCo to staff



Yearly handovers – “Passport” for rare conditions

Staff follow recommendations on PLP



Provision of accessible bathroom for intimate care and infection control

Allow independence for personal care where possible



Teaching Assistants involved in process / meetings

Consistent Teaching Assistant throughout Primary School



1. Can you describe an example/s of good practice with regards to your child's needs in school setting? What made the difference?

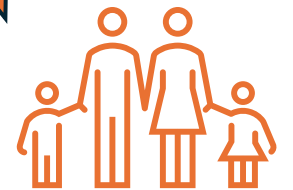
Exceptional Teaching Arrangements in place for school absences



Communication directly between Parents/ Caregivers and TAs



EPP- allergy to sunlight – Protective clothing managed well by staff and child kept away from windows. Pass given to stay indoors on sunny days



Bi-annual reviews and implementation of Statutory Assessment to ensure targets are addressed and achieved



Schools open to communication from Professionals and Parents



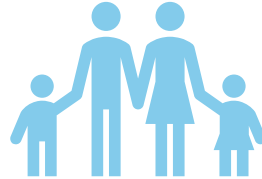
Listening to parents

1. Can you describe an example/s of good practice with regards to your child's needs in school setting? What made the difference?

Whole staff awareness / training for child with a rare condition



Medical / critical information shared (PKU, EPP)



Access Voluntary Sector Education Packages where available

Access specific training from Specialists (e.g Shine)



Home - school notebook

Good transition arrangements from Nursery – Primary- Secondary



2. Can you describe an example/s of poor practice in the school setting and explain what happened and any consequences from this?

Poor communication from school

Refusal to address specific training opportunities

Poor transition of information from year to year

Moderate LD school leavers – lack of qualifications in English and Mathematics – what next?

Transitions for children with LD – what is the best setting?

Exclusion from classroom activities

Discrimination/ exclusion due to rare diagnosis

Lack of training and willingness to learn about RD

Poor understanding of the child's needs specific to the condition (e.g 22q11 and mathematics)

Information on transport

Emotional vulnerability / anxiety not always addressed



2. Can you describe an example/s of poor practice in the school setting and explain what happened and any consequences from this ?

Guidance at transition stage on suitable school

Hidden disabilities – questioning the child

Dangerous practice with Medical conditions (child with EPP sent outside on hot day)

Child needs an advocate in school

School absences due to illness – lessons not sent home as arranged . Friends supplied the lessons.

Exclusion from PE outdoors at GCSE – no reasonable adjustments

“The whole process of secondary school was very stressful but perhaps the school was just not a good match for this child”

No accommodation to rejoin class after school absences

Parents not being listened to



2. Can you describe an example/s of poor practice in the school setting and explain what happened and any consequences from this ?

SENCOs need to advise parents re ETA process

Parents need to be involved in handovers **each year**

Training in medical conditions for TAs – need to have a standby in case TA absent.

Delays in starting school due to facilities and training

Lack of communication between school and parents

Help parents to understand SA process following diagnosis

Embarrassing questions re clothing (Problems with feet and non uniform footwear)

GDPR and sharing health /sensitive information



2. Can you describe an example/s of poor practice in the school setting and explain what happened and any consequences from this?

“Staff training should be compulsory, and awareness sought on the conditions of the child in order for the child to continue his education without feeling that they are a burden. Any child coming through the school with a SEN statement should not have to face any ignorance on their conditions. I provided all information regarding my son’s conditions also with pamphlets and internet links to the charities that provide the information they need to familiarise themselves with the conditions and how they affect the child.

Speak to the parents as they become the experts on this and take on board what they say. As each child is different, with my son’s diagnosis, communication is the key and the school cannot label each child as the same.”



Addressing needs of school staff



Rare condition does not require rare response

Be practical

Address individual needs as they arise

Learn about the condition

Learn about the child as a unique learner

Access literature / training where available

The child may need extra support with social / emotional development/ friendships due to absences from school

Addressing needs of school staff



Consider risks with Medical conditions and plan accordingly – welfare is paramount

Inform relevant staff on reasonable adjustments

Allow time to meet with parents each term – conditions and needs can change quickly

Please listen to concerns and advice

Recognise that many rare conditions are “hidden disabilities”

Parents are the experts in their child’s condition

Examples of links for Education in rare conditions

- [Education – Shine](#)
- [Home - The National Society for Phenylketonuria \(NSPKU\)](#)
- [Ehlers-Danlos syndromes – NHS](#)
- [22q11,2 deletion syndrome | About the Disease | GARD](#)
- [Duchenne UK](#)
- [Home - British Porphyria Association](#)

The way forward ...



RAISING
AWARENESS ON
EA WEBSITE



INFORMATION
AVAILABLE FOR
SCHOOL STAFF



FUTURE TRAINING
FOR LEARNING
SUPPORT
COORDINATORS
TO DISSEMINATE



SHARE LEARNING
OPPORTUNITIES IN
STAFF
DEVELOPMENT
DAYS

Template for an organic rare disease passport

- Specific to each child
- Living document: amended as the child's needs change throughout the school year

Child's condition

Year level:

Semester:

Meeting date:

Understanding the condition:

- -
- -
- -
- -

Emergency:

- -

Needs specific to the condition:

-
-
-

Impact of the condition on learning

- Motor skills
- Cognitive skills
- Fatigue/capacity to focus
- Social skills

Proposed learning strategy(ies)

-
-
-

Child's condition

Year level:
Semester:
Meeting date:

Understanding the condition:

- -
- -
- -
- -
- Emergency:
- -

Needs specific to the condition:

-
-
-

Other Impacts of the Condition on life at school

- Social skills
- Emotional development
- Digestive issues

Proposed strategy(ies)

-
-
-