



# MDVI Euronet

## Newsletter

### Special Edition December 2011

Welcome to this special edition of the MDVI Euronet Newsletter. We are dedicating this to a paper written by Patrizia Ceccarani et al of the Lego del Filo d'Oro Onlus, Osimo, Italy.

Those working with children and young people with Multiple Disabilities and Visual Impairment will know, through their experience, that the needs associated with this group have become more complex over the years. Indeed, when MDVI Euronet was established over a decade ago, one of the areas of work and interest for the network was to look at the changing needs of this population of learners.

In the time that has passed, Visual Impairment Scotland published a report entitled: "A new system of notification of childhood visual impairment and the information it has provided on services for Scottish children." (2003). In the wealth of information contained within this report, the researchers found that: "The majority of children with visual impairment (57.1%), had another disability in addition to visual impairment." Furthermore, "children with a visual impairment due to a condition of the brain are much more likely to have additional disabilities than children in whom visual impairment is due to eye or optic nerve disorders."

Now, this paper, based on research also presented at the DBI 2009 Conference, provides an extremely welcome and fascinating addition to the body of evidence into the changing needs of children and young people with a visual impairment. The paper provides an absorbing insight into the changing needs of the population of learners who have attended the Lega del Filo d'Oro's institute in Osimo over the past 40 years.

We hope you enjoy reading this paper.

Kind regards

Robert Jones

# **The Characteristics of Disabilities Arising from the Birth Process: an Epidemiological Study**

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## **Introduction**

The aim of this paper is to report on a project which explored the hypothesis that there has been an increase in frequency and gravity in forms of disability originating at the prenatal (from conception to birth) and perinatal stages (immediately before and after birth) in the cases seen by the Lega del Filo d'Oro's special unit. The research project was carried out between April 2006 and June 2007 in collaboration with the Epidemiological Unit of Ospedale Bambino Gesù, Rome. Retrospective analysis was used to evaluate the characteristics of a sample of cases in the Unit and the changes in these characteristics over time. The data obtained was used to give objective support in identifying the requirements and needs of an increasingly complex clinical/rehabilitation situation which, in our opinion, has emerged.

## **Objectives**

### **Main objective:**

To retrospectively examine the characteristics of users with pre and perinatal diseases in order to evaluate changes through time (from 1968 to 2007, over the 40 years of the Lega del Filo d'Oro's activity) in terms of:

- 1) type of disease;
- 2) etiopathogenesis of damage;
- 3) degree of disability and complexity of assistance requirements.

### **Specific objectives:**

- 1) to collect available data, bearing in mind the possibility of further future epidemiological analysis;
- 2) to construct an indicator of the complexity of the diseases which would summarise, in a single source, information coming from different variables;
- 3) to construct a program for collecting and computerising the data so that it can be used to give an overall perspective.

## Methodology

### Survey population

The survey population was made up of 381 users, both males and females, that had first accessed the Lega del Filo d'Oro between the ages of 3 and 8. The sample represents 32.6% of the total number of cases with pre or perinatal diseases (No= 1167), which have been treated at least once in the Special Unit in Osimo between 1968 and 2007. The users, subdivided into pre-school (3-5 years of age) and school groups (6-8 years of age), were included in order to have an exhaustive and homogeneous sample (table 1).

TABLE 1  
Age distribution at first contact

Age	N.	%
3-5	224	<b>58.8</b>
6-8	157	<b>41.2</b>
<i>Total</i>	381	<b>100.0</b>

### Data collection form

The form has 10 sections containing:

- Social-demographic information;
- pre and perinatal information;
- information about diagnosis (main and subsidiary), congenital malformations, surgical operations and current medical treatment;
- information on the state of health determined by the Unit in Osimo (with particular reference to ophthalmological, audiological, neurological, physical, orthopedic and dental conditions and cognitive and communication development);
- information relating to the degree of functional independence established by Unit in Osimo (including data on learning abilities, socialisation and autonomy).

Data was acquired by studying the clinical-educational-rehabilitation history, consulting the User Database and analysing Diagnosis and Assessment Questionnaires in order to collate information about all the users of Lega del Filo d'Oro between 1968 to 2007. A diagnosis classification was given using the Italian version of the International Classification of Disease – 9th revision – Clinical Modification – 2002.

## Statistical analysis

The analysis carried out was univariate and bivariate descriptive with examination of correlations and hypotheses of variable associations. The aim was to evaluate an analysis of the demand and its changes over time at the Osimo Centre, focusing on any lack of homogeneity and on time trends.

## Results

### General data relating to first contact with the Osimo Centre

Among the 381 users, there were 239 males (62.7%) and 142 females (37.3%). By distributing the population, by age and by decade according to first contact with the Unit, we can see a greater increase in users of age 3-5, in particular those of 3 and 4 years of age thanks to the early intervention policy practiced in the last twenty years (table 2).

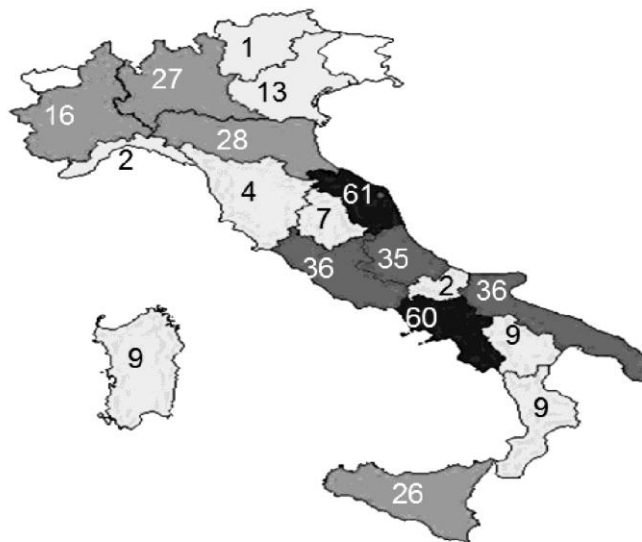
TABLE 2  
Decade of first contact with the Osimo Unit. Distribution by age

Age	3	4	5	6	7	8
<b>Users</b>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>
1968-1977	1	5	11	3	13	3
1978-1987	8	11	15	12	5	3
1988-1997	18	19	31	20	26	8
1998-2007	45	23	37	27	29	8
<i>Total</i>	72	58	94	62	73	22

The majority of patients (97.4%) are Italian children. The majority of cases at the Centre are “self-referrals” (76.7%) (figure 1).

FIGURE 1

Regional distribution of patients coming to the special unit in Osimo by decade of first contact.



## Perinatal cases

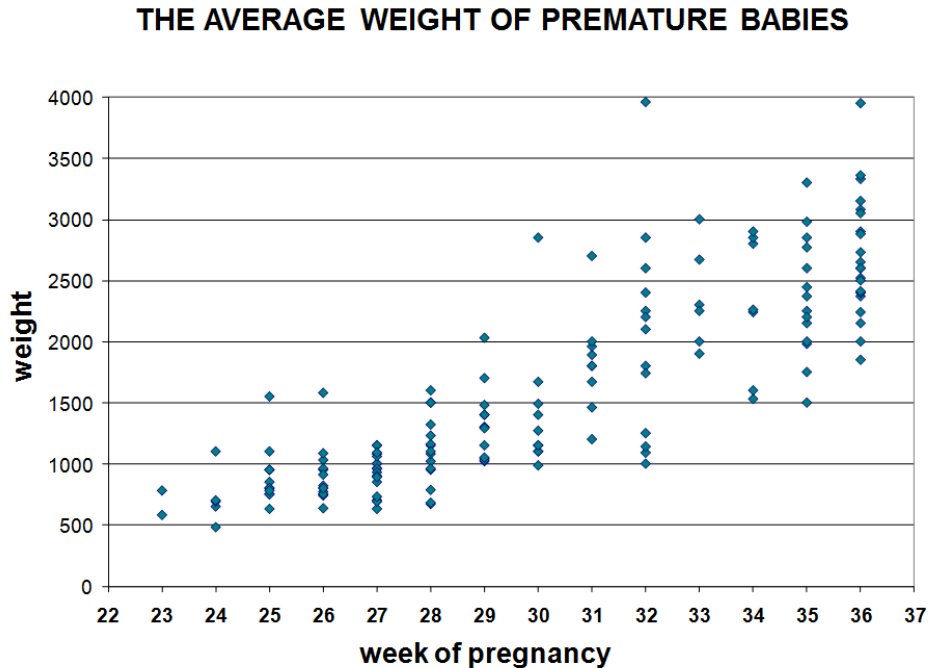
**Full-term births** (including post term ones) represent about 56% of the population and the majority were single pregnancies and natural deliveries. More than 83% of **premature births** were from single pregnancies with most being natural deliveries (53.6%). There was a slight increase in percentage in the number of premature births from multiple pregnancies (from 10 to more than 21%) and an increase in pre-term births (from 29.4% to 53%). These increases probably reflect the improved survival rates of pre-term births over the 40 years.

**The average weight of premature babies** is 1.6 kilos and the average length of pregnancy was 30 weeks (fig 2). The number of seriously premature births (< 32 weeks of pregnancy) is recorded at 98 (25.7%). Almost half of these (47%) were premature births at 26-28 weeks of pregnancy.

Foetal distress in babies born pre-term was reported in more than 80% of cases as compared with 32.8% of full-term births, with an increase of this percentage from 70% in the ten years from 1968-1977 to 87.5% in the last ten years (1998-2007).

The majority of babies resuscitated in the delivery room were born prematurely (69.2%) the most frequent intervention was giving oxygen with a general increase in the number of intubated patients, especially in the last ten years.

FIGURE 2



### Diagnostic summary

“Brain damage from prematurity” is the diagnosis in about 34% of cases. This seems to have increased over the 40 years with the percentage almost tripling from the 70s to the decade from 1998-2007. However, in contrast, it is important to note:

- 1) the frequency of the diagnosis of **brain damage caused by infection** during pregnancy is much reduced (it was nearly 53% of the population in the first decade and only 7.7% in the last);
- 2) the increase in **hypoxic-ischemic distress diseases** and **Central Nervous System (CNS)/unknown origin congenital brain damage**;
- 3) The substantial increase in **specific chromosome diseases** which in the course of the last two decades have appeared in clinical histories with a frequency of 7.7%.

The most frequent **malformations** in the population affect the eyes (32% of the reported malformations), followed by those of the CNS (23.3%). There does seem to be a gradual decrease in the number of patients with eye malformations.

**Surgical operations** undergone by the population are more likely to affect the visual system (28.6% of the operations) or be neurosurgical (9.4%).

## Ophthalmology section

For the population in question, 341 (89.5%) users have visual impairment or are blind to some extent. The number of patients who have a severe or very severe visual impairment seems to have undergone a change over the years, from more than 88% in the 70s to about 58% in the last decade.

The percentage with sight impairment is high in both groups (pre-and full term) with greater prevalence in the preterm births. In both groups, severe or very severe sight impairment is more frequent (table 3).

TABLE 3  
Hypovision\* by length of pregnancy

Users		1968-1977 (n = 33)	1978-1987 (n = 50)	1988-1997 (n = 106)	1998-2007 (n = 150)	Total (n = 339)
<b>Hypovision</b>						
Pre-term		10	25	40	81	156
Full term		23	25	66	69	183
<b>Extent of hypovision</b>						
Pre-term	Slight/medium	-	4	13	29	46
	Severe/very severe	10	21	27	52	110
Full term	Slight/medium	3	5	21	24	53
	Severe/very severe	20	20	45	45	130

(\*Hypovision: loss of vision that cannot be corrected by normal means of vision correction leading to a visual disability.)

The most common cause of visual impairment in the population is optic atrophy (39.3%), followed by ROP (20.8%) and then congenital cataracts (12.9%). There is, however, an appreciable decrease in the number of congenital cataracts. The majority of patients with vision problems wear corrective lenses for both eyes (99%) (table 4).

TABLE 4

## Most frequent causes of visual impairments by decade of first contact

	1968-1977	1978-1987	1988-1997	1998-2007	Total
	(%)	(%)	(%)	(%)	(%)
Optic atrophy	20.0	26.5	40.6	47.0	39.3
ROP	8.6	34.7	20.8	19.2	20.8
Congenital cataracts	57.1	16.3	10.4	3.3	12.9
Coloboma	-	2.0	4.7	8.0	5.3
Congenital glaucoma	-	2.0	0.9	3.3	2.0

## Hearing Section

### Hearing organs and total diagnostic-functional evaluation by decade of first contact

For the survey population, there are 146 (38.3%) users with hearing impairments of various types: 76% have a severe or very severe hearing impairment, a percentage which has remained more or less the same through the years (table 5). However, the percentage of hearing impairment is higher in full term babies (table 6). In both groups, severe/very severe hearing impairment is the most common type. Users with undamaged hearing organs represent almost 62% of the population.

TABLE 5

## Etiology of hearing impairment by decade of first contact

	1968-1977	1978-1987	1988-1997	1998-2007	Total
	(%)	(%)	(%)	(%)	(%)
Hearing impairment/ deafness	69.4	29.6	35.3	36.7	38.3
Slight	-	-	4.7	6.5	4.1
Medium	4.0	6.3	-	16.1	8.2
Severe	28.0	43.8	16.3	27.4	26.0
Very severe	60.0	25.0	60.5	45.2	50.0
To evaluate	8.0	25.0	18.6	3.2	11.0
Undamaged	30.6	70.4	64.8	63.3	61.7



The most common type of hearing impairment is neurosensory (89.7%) and the most common cause is congenital malformation (40.4%). This appears to have increased in the decades analysed (from 20% to 51.6%), followed by infection (29.4%) which, on the other hand, seems to have decreased through the years. Hearing impairment from perinatal asphyxia is 28.8% and this figure seems to have been quite stable over the last 30 years. The majority of patients with hearing impairments (68%) have received prescriptions for corrective treatment which in 94% of cases is a behind-the-ear hearing aid.

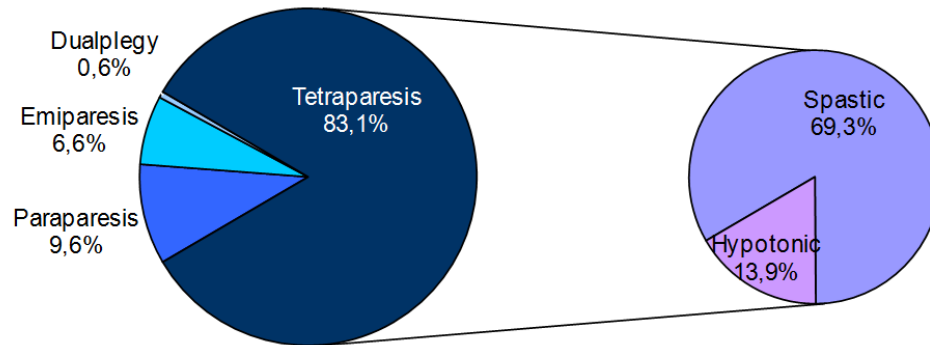
**TABLE 6**  
Hearing organ characteristic according to length of pregnancy

	<b>1968-1977</b>	<b>1978-1987</b>	<b>1988-1997</b>	<b>1998-2007</b>	<b>TOTAL</b>
<b>N. USERS</b>	<b>(n = 24)</b>	<b>(n = 16)</b>	<b>(n = 43)</b>	<b>(n = 61)</b>	<b>(n =144)</b>
<b>HEARING IMPAIRMENT</b>					
Pre-term	6	3	11	28	48
Full term	48	13	32	33	96
<b>TYPE OF IMPAIRMENT</b>					
Pre- term   Slight/medium	-	1	-	7	8
Severe/very severe	6	2	11	21	40
Full term   Slight/medium	3	4	10	9	26
Severe/very severe	15	9	22	24	70

## Neurological Section

Significant difficulties relating to autonomy in daily living and epilepsy are the two important clinical variables with respect to disability and dependency. Of the total population, 43.6% have motor problems. In the course of the period studied, the number of these patients has increased by about 10% every ten years (from about 20% in the 70s to about 53% in the last decade). Tetraparesis is the most common type of problem and through the years the occurrence has remained fairly stable (figure 3).

FIGURE 3  
Distribution of motor problems



In about 55% of the population, walking is not possible or requires the use of supports or aids. This has increased through the decades: in 1968-77 the percentage was about 20%, while it has gone up to about 65% in the last decade. More than 80% of the population arrived at the Unit with rehabilitation activities already under way. The most commonly recommended treatment is physiotherapy (91.1% of the total), followed by speech and language therapy (68.2%), music therapy (53%) and Oral Motor (chewing) (48%). Through the years, the number of users who have been prescribed specialised rehabilitation therapy has increased.

### Cognitive, Communication and Autonomy Section

On the base of classifications used in the literature, three main dominions of disability were studied (neuromotor, sensory and cognitive-linguistic disabilities) to establish their frequency and any changes to them over time in users with deficits in 1 or more of the dominions. It was established that many users have a deficit in one or more category (figure 4).

FIGURE 4

	severe disability 1 Dominion	severe disability 2 Dominions*	severe disability 3 Dominions**
381 CASES	347 (91%)	178 (51%)	87 (23%)

\*Neuromotor+sensory or neuromotor+cognitive-linguistic or sensory+cognitive-linguistic.

\*\*Neuromotor, sensory and cognitive-linguistic.

Almost 23% of the population has a severe deficit in all three of the dominions, taking into account one child in the 70s and now one in every 51. Severe disability is more often found in the sensory category (78% in total). 37% of the population have severe/very severe intellectual disability.

Groups with an intellectual disability (19%) and developmental delay (30%) which were diagnosed on subsequent visits to the Centre have been included in severe/very severe intellectual disability because, according to our experience, these types of delay frequently become a severe or very severe intellectual delay.

Table 7 shows the frequency of users with severely compromised autonomy in various aspects over each of the decades studied. It is noticeable that in each decade, the occurrence of “non autonomous” children is more and more frequent in comparison to those who are partially dependent or totally independent. In fact, 81.1% of users seem to be dependent at least on one category and this percentage increases over time. The percentage of independent children is 1% and this decreases over the decades.

TABLE 7  
Daily skills

	1968-1977		1978-1987		1988-1997		1998-2007		TOTAL	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
	(n=36)		(n=54)		(n=122)		(n=169)		(n=381)	
<b>Drinking from a glass</b>										
No/dependent	25	(69.4)	38	(70.4)	85	(69.7)	100	(59.2)	248	(65.1)
Yes, with help	4	(11.1)	11	(20.4)	17	(13.9)	37	(21.9)	69	(18.1)
Yes, alone	7	(19.4)	5	(9.3)	20	(16.4)	32	(18.9)	64	(16.8)
<b>Eating with cutlery</b>										
No/dependent	25	(69.4)	38	(70.4)	85	(69.7)	106	(62.7)	254	(66.7)
Yes, with help	4	(11.1)	14	(25.9)	23	(18.8)	43	(25.5)	84	(22.0)
Yes, alone	7	(19.4)	2	(3.7)	14	(11.5)	20	(11.8)	43	(11.3)
<b>Washing hands/face/body</b>										
No/dependent	27	(75.0)	43	(79.6)	98	(80.3)	135	(79.9)	303	(79.5)
Yes, with help	7	(19.4)	11	(20.4)	24	(19.7)	32	(18.9)	74	(19.4)
Yes, alone	2	(5.6)	0	-	0	-	2	(1.2)	4	(1.1)

<b>Getting dressed</b>										
No/dependent	28	(77.8)	43	(79.6)	96	(78.7)	134	(79.3)	301	(79.0)
Yes, with help	5	(13.9)	11	(20.4)	24	(19.7)	31	(18.3)	71	(18.6)
Yes, alone	3	(8.3)	0	-	2	(1.6)	4	(2.4)	9	(2.4)
<b>No/dependent almost in 1 dominion</b>	28	(77.8)	43	(79.6)	98	(80.3)	140	(82.8)	309	(81.1)
<b>No/dependent or with help almost in 1 dominion</b>	34	(94.4)	54	(100.0)	122	(100.0)	167	(98.8)	377	(99.0)
<b>Independent in all the dominions</b>	2	(5.6)	0	-	0	-	2	(1.2)	4	(1.0)

To better evaluate the level of dependency associated to the severity of users' disability in the population in question, we created a dependency/severity indicator which takes account of the individual's motor, linguistic and sensory (sight and hearing) skills at the same time as autonomy in daily living. The dependency/severity indicator provides an average assessment of the severity of each case. Table 8 shows there has been an increase in very severe cases, which goes from 16.7% in the 70s to 27.2% in the last decade. At the same time there has been an increase in the least severe cases (from 14% to 30%), a reduction in severe cases, especially since the start of the second decade and some stability in the medium severity cases.

The occurrence of premature babies with severe and very severe dependence/gravity increases steadily in comparison with those with medium degree. The number of patients with slight disability remains more or less constant over time.

TABLE 8  
Level of dependence/severity by decade of first access

	<b>1968-1977</b>		<b>1978-1987</b>		<b>1988-1997</b>		<b>1998-2007</b>		<b>TOTAL</b>	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
<b>Slight</b> (<1.0625)	5	(13.9)	12	(22.2)	33	(27.1)	50	(29.6)	100	(26.3)
<b>Medium</b> (>1.0625 e <= 1.625)	9	(25.0)	16	(29.6)	30	(24.6)	39	(23.1)	94	(24.7)
<b>Serious</b> (>1.625 e <=2.125)	16	(44.4)	15	(27.8)	30	(24.6)	34	(20.1)	95	(24.9)
<b>Very serious</b> (>2.125)	6	(16.7)	11	(20.4)	29	(23.7)	46	(27.2)	92	(24.1)

Through the years, the degree of dependency/gravity has increased only in those users with hypoxic-ischemic damage, which goes from medium to severe degree. Degrees of severity are more or less constant in time for other causes (table 9).

TABLE 9  
Etiology for degree of dependence/severity

<b>ETIOLOGY</b>	<b>Slight/medium</b> (%)	<b>Severe/very severe</b> (%)
Hypoxia/anoxia/asphyxia	33.3	66.7
Prematurity/IHV/PVL	48.1	51.9
Malformation	46.8	53.2
Infection	54.7	45.3
Genetic/chromosomal	72.6	27.4

## To summarise

1. **Pathologies and frequency:** brain damage from premature birth has almost tripled over the years studied. Brain damage as result of infection during pregnancy has reduced by about 7 times. An increase is clear in hypoxic-ischemic distress pathologies and CNS/unknown origin congenital brain damage malformations. There is a substantial increase in specific chromosome diseases.
2. **The complexity of problems:** about 96% of patients have a severe deficit in at least 1 category (sensory, neuromotor or cognitive) with nearly 23% having one in all three categories (highest severity).
3. **Degree of dependency:** uniformly distributed among slight, medium and high degrees, but over time only the highest and the slight degrees have increased in number.
4. **Preterm:** The number of preterm children with a high or very high degree of dependency has increased more in comparison with the rest of the population.
5. **High Dependency:** The percentage of users with high to very high dependency correlates with hypoxic-ischemic damage, while the percentage of users with a slight-medium degree of dependency is prevalently linked to genetic causes.
6. **Population:** The child population aged between 3 and 8 years old referred to the Special Unit in Osimo, comes from all over Italy and the catchment has grown with time.
7. **Osmino Centre:** There are various factors which have influenced changes over time: greater specialisation in the Centre, growing national awareness and geographical position.

This research probably reflects the situation in Italy in the last 40 years given that the **Special Unit in the Lega del Filo d'Oro** is a potentially very important focal point for understanding the nature and extent of these problems in our country and how the users' needs, types and amounts of assistance could change.

Our study is now continuing with the aim to evaluate the users, aged between 3 to 8 years, present at the

Lega del Filo d'Oro from 2007 to 2012, so we can have a complete picture of the 45 years of the work undertaken at the Lega del Filo d'Oro.

### **Acknowledgement**

The authors would like to thank Robert Jones of St Joseph's Primary School for Children with Visual Impairment for his assistance in preparing the English language version of this paper.

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**December 2011**