

THE NEEDS OF THE FAMILIES OF CHILDREN WITH AUTISM: A SURVEY WITH TWO GROUPS OF PARENTS

We present the first data regarding a survey using a questionnaire done with two groups of parents of children with Autism or other PDD. In the first group there are parents resident in the district of Cuneo, an area with several small towns. The second group are parents resident in the City of Turin, an industrial town with 1 million inhabitants. The survey has been made with the collaboration of the City of Turin, the ASL 4 of Turin (a Local Health Unit) and an Association of Parents (ANGSA). The regional Assessorship of Health and Assistance also contributed to the survey.

AIMS OF THE SURVEY

- To know the kinds of diagnostic and rehabilitative procedures followed by individuals with Autism
- To know the opinion of the Parents on the quality of the services provided by the National Health Service, the Local Authorities and the School.
- To identify the needs of the parents of children and adults with Autism.
- To return the data to the Authorities in order to improve the quality of the services for Individuals with Autism.

METHODOLOGY

The survey has been made using a questionnaire given to the Parents.

THE QUESTIONNAIRE

- It contains 43 items
- 42 questions have multiple choice
- 1 question is open

Areas of survey

- Services provided during diagnostic course
- Rehabilitative and school course
- Family changes caused by the handicap
- Characteristics (abilities and disabilities) of the child
- Opinions of the Parents about Social and Health Services and about the integration at School
- Suggestions of Parents to the Institutions

FIRST OUTCOMES AND DISCUSSION

IN THE FOLLOWING TABLE ARE FOUND SOME OF THE MOST SIGNIFICANT OUTCOMES OF THE QUESTIONNAIRE.

THE RESEARCH IS STILL IN PROGRESS IN THE CITY OF TURIN.

NUMBER OF RETURNED QUESTIONNAIRES: 30

Table 2. INTEGRATION AT SCHOOL

AGE	ENTRANCE IN NORMAL SCHOOL/CRECHE	APPOINTMENT OF SUPPORT TEACHER
0-3 Y.	40%	16.7%
3-4 Y.	43.3%	33.3%
4-5 Y.	10%	20%
> 5 Y.	6.7%	30%

Table 4. NEEDS AND REQUESTS (SUGGESTIONS) OF PARENTS TO THE SERVICES

IMPROVE THE PHASE OF DIAGNOSIS	43.3%
IMPROVE THE TRAINING AND FORMATION OF OPERATORS AND TEACHERS	43.3%
REDUCE THE TURN OVER OF PROFESSIONALS AND TEACHERS	33.3%
SUPPORT FOR LEISURE TIME	30%
PROVIDE MORE INFORMATION ABOUT AUTISM TO THE FAMILY	26.7%
CREATE DAY-CENTRES AND COMM. FARM	26.7%
INCREASE THE NUMBER OF OPERATORS AND SERVICES	23.3%
IMPROVE THE COLLABORATION BETWEEN SERVICES, SCHOOL AND FAMILIES	16.7%
IMPROVE THE REHABILITATIVE STRUCTURES	16.7%
MONEY CONTRIBUTION TO THE FAMILIES	13.3%
PSYCHOL. SUPPORT TO THE FAMILIES	13.3%
ORGANISE PROFESSIONAL TRAINING COURSES AND WORK INTEGRATION	6.7%

The complete results will be displayed shortly on the Internet Site www.alihandicap.org/ali, or can be requested at the e-mail address alimondovi@infosys.it

Table 1. AGE AT TIME OF FIRST REQUEST OF HELP, OF DIAGNOSIS AND OF INTERVENTION

AGE	FIRST REQUEST OF HELP TO FAMILY DOCTOR	FIRST DIAGNOSIS OF AUTISM OR OTHER PDD	BEGINNING OF REHABILITATIVE INTERVENTION
< 1 Y.	36%	7.2%	
1-2 Y.	24%	3.6%	11.2%
2-3 Y.	20%	25%	22.2%
3-4 Y.	16%	25%	37%
4-5 Y.		17.8%	14.8%
> 5 Y.	4%	21.4%	14.8%

Table 3. OPINIONS OF PARENTS ABOUT SERVICES

OPINION ON:	VERY GOOD	QUITE GOOD	QUITE BAD	VERY BAD
SCHOOL	69%	17.2%	6.9%	6.9%
HEALTH SERVICES AT MOMENT OF DIAGNOSIS	27.6%	38%	6.8%	27.6%
CURRENT REHABILITATIVE INTERVENTIONS	56.7%	40%	3.3%	
SOCIAL SERVICES	47%	41.2%		11.8%
COLLABORATION BETWEEN SCHOOL, SERVICES AND FAMILY	63.3%	13.3%	6.7%	16.7%

CONCLUSIONS

- The first results of the survey suggest that the main needs of the families are:
- the need to improve the diagnostic phase, in particular the early diagnosis
 - the need to start the rehabilitative program earlier
 - the need to improve the training of professionals and teachers and to reduce the turn-over
 - the need to find support for leisure time of the child
 - the need to receive more detailed information
 - the need to create structures and centres for adults
- It should be noted that the majority of the questionnaires (25/30) were completed by parents of subjects with autism under 15 years old