



Education and Culture DG

Lifelong Learning Programme

## Professional Training of Parents of Syndrome Down Children



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**WP 2: ANALYSIS NEEDS**

**FOCUS GROUP**



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## FOCUS GROUP INTRODUCTION

From the very beginning an evaluation was made of the need to complement and contrast the information gathered from the surveys with the contributions of a more qualitative nature that we would obtain through the focus group.

Such an approach would allow us to obtain first-hand data and opinions from the groups of persons that play a significant role in the life of people with Down syndrome.

On one hand, the families would have a place and time that will enable them to develop, discuss, contrast and qualify the opinions and experiences described in the survey. The families that answered the questionnaire were able to inform us voluntarily of their interest and readiness to take part in these discussion groups, and also supply their personal details, which would enable us to contact them and inform them about the features of the groups and the dates and times of meetings.

Furthermore, we believe that the opinion of various professionals working with people with Down syndrome enabled us to obtain a much fuller analysis, and meant that we were able to achieve a far more objective contribution from various different angles. Apart from the direct work done by these professionals, in most cases there is coordination and even direct intervention by the families, and thus we are able to compile a list of needs, experiences, doubts, and difficulties with a large group of implicated people. Furthermore, the specialisation of these professionals leads to a more far-reaching depth and detail in each of these fields. In many cases, contact with these professionals was made through the channels of coordination established several years ago by the Foundation with community resources from our city (educational centres, health, social work, etc.).

Both the family groups and the groups of professionals were divided into the same age ranges as the questionnaires, since we believed the needs, feelings and demands are significantly different in each of these stages of life.

On the other hand, we also considered it to be of vital importance that the people themselves that were suffering from Down syndrome should have the chance to express their demands and experiences personally. To do so, we enjoy the collaboration of a stable and highly active group composed of 15 youngsters and adults that use the Foundation's facilities, and meet together every week to produce a newspaper.

## METHODOLOGY

A Focus Group is a qualitative, exploratory technique for gathering information. It works by creating an open and moderated discussion based on a specific topic among a group of previously selected people.

The Focus Group's purpose is to collect first-hand information through the opinions and insights from people who have a relevant role in the topic discussed.

The main aim of a Focus Group is to achieve an interactive, dynamic group, in other words, the response of one person is capable of being an encouragement for another person. Through this an exchange of answers is generated with much better results than if the participants of the group had contributed independently.

The Focus group understands and analyses the results obtained from a questionnaire-style survey and subsequently introduces these conclusions into the debate.

Generally, the Focus Groups are led by a moderator. The moderator has to take into account the following matters:

- condensing the questions: ensuring the list of questions is not too long
- avoiding questions expressed in an alternative form
- assuring all participants have time to express their opinions
- summarising each question and asking the participants to express their views on the matter
- rewording questions if they have not been understood
- taking body language (nodding or shaking of the head, smiling, etc) into account.
- preventing one person from dominating the discussion.
- maintaining a balance in the participation of different people.

The discussion duration must be estimated before the session commences. In this case, we believe that two hours will be enough.

The number of participants must also be established. In our case, the number of participants will range between 8 and 12 people. All of them must have a relationship with people with Down's syndrome whether they are family members or are professionals who are directly related.

A register of the names and surnames of those present will be taken.

We will explain the motive of the group, the duration and the group methodology to the participants. The participants are introduced to each other and they are informed that the discussion will be recorded.

Throughout the discussion, it is advisable to take notes on a blackboard or any other shared visual tool. The moderator will end the discussion with a summary of the information, to confirm the result and check that there are no disagreements or misunderstandings. The presentation will be informal.

Recording the discussion is a good way in saving information on the session development progress and the debate contents. This method enables all the contents of the different discussions to be preserved.

## SELECTION OF PARTICIPANTS

### A/ FAMILY GROUPS

Four age groups are established: 0-6 years, 6-18 years, 18-40 years, more than 40 years.

Preferably the father/mother will attend. In the older age groups brothers and sisters can also take part (as we understand that the parents' ages may prevent their attendance).

Wherever possible only one member of the family unit will attend (if we do not have sufficient number of participants two members per family unit can attend)

Participation in the group will be voluntary.

The questions asked in the discussion will be:

- At what point throughout my experience have I felt alone, that I did not have enough information or I felt that I had no support?
- What positive aspects of my experience as a parent of a person with DS stand out?

- What are the negative aspects and how do I think they could improve?

### B/ GROUP OF PROFESSIONALS

Professionals should be practising at the moment of participation; it is advisable that they have a professional experience of direct involvement with people with DS and their families.

The groups are established by age groups, in the same way as family groups.

Below we have a list of possible professionals who could participate, however, all professions must be represented.

0-6 years paediatricians, other specialists: Cardiology, endocrinology, rehabilitation doctor, psychologists, early intervention specialists, primary schools teachers, social workers, speech therapists.

6-18 years paediatricians, other specialists: Cardiology, endocrinology, etc... mainstream school and special education centre teachers, psychologists, speech therapists, social workers, free time monitors.

18-40 years: family doctors, gynaecologists, psychiatrists, psychologists, social education teachers, social inclusion mentors, work preparation coaches, social workers

Over 40 years one-on-one attention staff from welfare centres, psychiatrists, neurologists, work preparation coach, family doctor, psychologists, social worker.

The questions asked in the discussion will be:

- From your experience with dealing with the families of people with DS, according to you what are their needs?
- What demands do you hear on a daily basis from these families?
- How do you think that the design of this tool could be more suitable for the families, so that it is easily accessed?

### C/ GROUP OF PEOPLE WITH DS

In this case, there will only be one group with the only requirement that that they are over 18 and participation is voluntary.

The questions asked in the discussion will be:

- How has your family helped you?
- What topics would you like to talk about with your family that you haven't approached?
- Have you ever spoken to your family about DS?
- If someone asked you to talk about people with DS, what would you tell them?

## GRUPO DE DISCUSIÓN PROFESIONALES QUE INTERVIENEN DE 0-6 AÑOS

### COMPOSICIÓN DEL GRUPO

El grupo está compuesto por profesionales del ámbito sanitario, educativo y de recursos sociales que atienden a personas con SD en esta franja de edad.

### NECESIDADES DE LAS FAMILIAS PERCIBIDAS POR LOS PROFESIONALES

Todos los profesionales coinciden en la necesidad para las familias de una **buena comunicación**, por parte del personal sanitario, de la noticia del nacimiento de la persona con síndrome de down, ya que luego observan que es un tema recurrente de conversación en las familias que, en general, recuerdan de forma muy negativa. Verbalizan que **la información debe darse de manera positiva, clara, veraz y a la mayor brevedad posible**, para reducir los momentos de incertidumbre y ansiedad del momento.

*"es muy importante el cómo se recibe, quién la tiene que dar, cómo se debe de dar, quién la debe de recibir".*

*"...intentar que la noticia sea individualizada, personalizada, que haya una cierta intimidad..."*

*"los papás verbalizan que la incertidumbre hasta que conocen la noticia, es lo peor"*

*"Cuando se les tiene que decir algo, se les diga de forma clara, muchas veces no hablamos con los papás, es peor la incertidumbre de estar en un si y en un no..."*

*"...por una parte está quien te la da, pero por otra parte está quien te la recibe, que no todas las personas somos iguales y por mucho cuidado que se ponga habrá personas que tengan un bagaje y un desarrollo personal y habrá otras que no lo tengan..."*

*"A la familia hay que darle la información de lo que te pide, tampoco pasarnos. Hay que ser real, veraz, no hay que ocultar nada..."*

El personal sanitario apunta que es aconsejable que **la noticia la dé el médico a la pareja junta**, aunque reconocen que no siempre es así debido a la **falta de profesionales especializados** y a pesar de disponer de un protocolo de intervención ante el nacimiento de un niño con síndrome de down. También acusan la **falta de espacio y tiempo**, desde el ámbito sanitario, para comunicar la noticia.

*"Existen protocolos sobre la información a la familia sobre los cuidados de un niño con síndrome de down. En maternidad los profesionales no familiarizados con la materia, ya lo están. Cuando conocen o saben que nace un niño, van al protocolo".*

*"La primera noticia tienen que saber como la tienen que dar y transmitir".*

*"Los profesionales deben estar preparados y formados para saber que nos están pidiendo. Dentro de que no puede ocultarse nada"*

*"Creo que es necesario formar a las personas que están en un hospital de cómo entender a estas personas, pero de formar, no que haya un protocolo..."*

Consideran que en los primeros momentos de vida del niño, es necesario que exista una **buena coordinación entre los profesionales que están interviniendo y que estén bien cualificados**, ya que la ayuda de los profesionales es fundamental. Reconocen que hay muchos fallos de los profesionales y **las familias demandan formación profesional especializada y cuidado en el trato**.

*"se detecta en los padres, que les genera mucha ansiedad, la descoordinación o intrusismo de un profesional en el ámbito del otro"*

*"a los padres les tranquiliza mucho que todo el mundo, la información que les vayamos dando, sea siempre la misma"*

Una vez confirmado el diagnóstico, desde el ámbito sanitario, se apunta siempre que sea posible la **importancia de la organización de los cuidados, haciendo partícipes a ambos padres y la cohabitación desde el primer momento con la madre.**

*"No alejar al niño de la madre, la cohabitación es importantísima para que no exista el rechazo, cuanto antes lo tenga, lo conozca y lo vea existe menos rechazo posterior..."*

*"Que se favorezca la lactancia materna también es muy importante porque el vínculo de la madre con el niño no se rompe, se aumenta".*

Así mismo se incide en la **necesidad de hablar con los padres de lo que se va a hacer de manera más inmediata tras el alta médica.** Para ello plantean la importancia del apoyo de los especialistas en atención temprana (rehabilitación)

*"La estimulación temprana empieza desde el hospital y ya salen con una entrevista con el rehabilitador y además con una hojita para iniciar todo lo que viene detrás" "... y después hay una serie de exámenes de salud que hay que hacer, como es un estudio cardiológico, porque todo eso va a condicionar la evolución del niño".*

En este sentido, también destacan la importancia de **establecer un puente entre la atención especializada y la primaria** porque consideran que debe darse una continuidad que en la actualidad no existe y ahí, entienden, que radica el fracaso o todas las dudas y ansiedades de las familias.

*"Si hubiese una buena continuidad con la atención primaria, yo creo que mejorarían mucho las cosas".*

Están de acuerdo en la **importancia del apoyo de la familia de los padres** (abuelos, hermanos,...) y ven como una necesidad para las familias implicarles desde el primer momento.

*"Es importante también el grupo familiar que los conoce. Los abuelos lo ven como algo insalvable, que no van a superar nunca, algo que les ha venido de no saben donde. Eso no nos interesa, pero si gente joven, hermanos, familiares,..."*

Así mismo, consideran fundamental el **apoyo desde las asociaciones y el contacto con otros padres de niños con síndrome de down**, desde el momento del nacimiento.

*"el contacto con la gente que tiene el mismo problema, les allana mucho el camino, dicen "oye que no pasa nada..."."*

*"le ayuda no quedarse solos, que sepan que van a encontrar apoyo en las asociaciones,..."*

*"se personan parejas que tienen conocimiento del problema y que lo han vivido anteriormente y que pueden ayudar muchísimo..." "... el hecho de ver una pareja que ya ha pasado por ese instante, por ese problema, los padres reaccionan de forma diferente y asumen el problema rápidamente y se ponen enseguida a trabajar..."*

## NECESIDADES QUE DEMANDAN LAS FAMILIAS A LOS PROFESIONALES

El **momento del nacimiento** del niño con síndrome de down es crucial para las familias. En este aspecto hay pleno consenso de los profesionales. Coinciden en que las familias demandan rapidez en el diagnóstico y una información buena y veraz a la hora de comunicar la noticia, ya que se enfrentan a un momento de gran incertidumbre. Así mismo, demandan mayor formación y especialización de los profesionales y cuidado en el trato.

*"...los papás verbalizan que esta incertidumbre es lo peor..."*

*"...cuando se les tiene que decir algo, se les diga de forma clara. Muchas veces no hablamos con los papás, es peor la incertidumbre de estar en un sí y en un no..."*

Conocido el diagnóstico, los profesionales indican que, enseguida **reclaman la ayuda de otros profesionales que intervienen, grupos de apoyo o asociaciones y tienen la necesidad de manejar mucha información respecto al síndrome de down**, fundamentalmente, *"existe mucha inquietud e incertidumbre a nivel sanitario y educativo"*.

*"...lo quieren saber ya todo, una vez que lo asumen y que lo asumen rápidamente, quieren saber lo que va a pasar, "que tengo que hacer"..."*

*"... las familias preguntan al principio, ¿es mucho o es poco?"*

*"las reacciones de estas familias pueden ser muy diversas, necesitan mucha información, de saber qué pueden esperar..."*

*"La información la van demandando durante los primeros años de vida bastante a menudo y muchas veces hay que repetir las misma cosas..."*

Por otro lado, aunque la intervención temprana está programada, señalan que algunas familias lo consideran insuficiente.

*"...yo creo que sobreestimulan a los niños, los apuntan a todo, los llevan aquí, los llevan allá..."*

El tema de la **escolarización** en guarderías o escuelas infantiles, es otra preocupación generalizada en las familias. Según los profesionales que intervienen en esta etapa junto con el momento del nacimiento es uno de los aspectos que más inquietud y ansiedad provoca. Los padres demandan mucha información a nivel general y en especial acerca de la formación o especialización que tienen los profesionales que van a atender a sus hijos.

*"Desde el primer momento, surgen inquietudes de cara al futuro, como éva a poder ir a integración?"*

*"Antes de empezar la apertura de las plazas escolares, las familias están ya - a que centro, se adelantan,..."*

Los profesionales destacan que las familias también acusan la **falta de formación, especialización y sensibilidad** de algunos profesionales del ámbito educativo, a pesar de que entre algunos profesionales existe la convicción de que tienen buena voluntad.

*"... ha habido padres que se encuentran con el rechazo y cuando hablas con los coles si que se encuentran mucho "que hago, como lo trato..."*

*"A veces los profes, continuamente citan a los padres y comentan a los padres las cosas de las que carecen. Sólo se habla de lo que les falta, de los objetivos que vamos a alcanzar, más allá, más allá,... y pocas veces se habla de las cosas que han conseguido o que ahora mismo son".*

*"...falta formación, estamos coordinados con los profesionales y se ve que los quieren y quieren que avancen, pero les falta formación."*

Por último, a nivel social, los profesionales recogen la **necesidad de apoyo** que tienen los padres, en especial las madres como cuidadoras principales.

*"...veo la necesidad de desconectar las madres del problema porque enseguida se exigen el papel de cuidadoras principales, dejan de trabajar,..."* *"...debería haber apoyos y no los hay"*

*"...la madre deja de trabajar, con lo cual hay una merma de ingresos económicos familiares, un aumento de gastos y además no cotizan a la seguridad social..."*

## PROPUESTAS PARA EL DISEÑO DEL DVD

- Claridad y objetividad
- Positivismo
- Que se transmita la idea de que las familias normalicen sus vidas, las madres no dejen de trabajar y busquen ayudas.
- Sería interesante el testimonio de otras familias.
- Que sea muy general, que no comprometa a nada, muy aséptico, muy cuidado.
- Ni muy optimista ni muy pesimista.
- Reflejar fundamentalmente, los medios (profesionales, servicios, asociaciones, profesores de apoyo...) de los que se puede beneficiar el niño con síndrome de down y la familia.
- Discrepancias entre el grupo de profesionales sobre si incluir información de juegos generales de disfrute para que los padres los hagan en casa.
- Transmitir que existe un buen soporte sanitario (buenos especialistas) y la seguridad de que su niño va a estar bien tratado. Es fundamental para las familias que sepan que están en las mejores manos.
- Mostrar que existe la atención temprana, la rehabilitación en los hospitales y el apoyo escolar.

## FOCUS GROUP, PROFESSIONALS, 6 to 18 year-olds.

### COMPOSITION OF THE GROUP

The group is formed by various professionals, representing the areas of health, education and therapy, and social involvement, through specialised programmes for Leisure, Sports and Free Time Activities.

### PRESENTATION OF THE GROUP

The moderators of the group start by introducing the various participants of the group along with the methodology adopted.

The structure of the session will be divided up as follows;

- Formulation of the first question
- Time to contribute ideas and discuss
- Conclusions
- Formulation of the second question
- Time to contribute ideas and discuss
- Conclusions
- Formulation of the third question
- Time to contribute ideas and discuss
- Conclusions
- Farewells and closure of the meeting

### QUESTION NUMBER ONE, AS PROFESSIONALS, WHAT INFORMATION DO THE FAMILIES OF PEOPLE WITH DOWN SYNDROME ASK YOU FOR?

We shall divide the contributions of the professionals according to the areas reflected in the questionnaire;

## 1. HEALTH:

The Paediatricians' responses distinguish between two different types of enquiries made by the families:

- At critical moments like the birth of the child, for instance, in which the families ask for a vital prognosis of their child with DS, along with information on the quality of life that can be expected during their development. This is also the time when severe health problems are diagnosed, such as heart diseases, neurological problems, etc. The consultants point out that this moment requires communication with the parents to be handled very sensitively, offering careful, positive information
- Another moment for consultation is during times of minor importance, such as puberty and development. At such moments the families are less anxious when they visit the clinic. They are also less demanding, seeking information on the following:
  - Prediction of adult height; information on how this might be improved
  - Onset of puberty: whether it is early or not, and if it is, how this will affect the child's relationship with others, their sexual interest, etc.
  - Hormone and thyroid problems and how to treat them...
  - Information regarding the childcare programme for their children: they have a desire to be aware of the type of health problems that might arise during their child's development.

*"...I deal with less serious problems, growth, puberty, the hormone issue...when the parents come to me, they are less demanding. They have already been through the tidal wave caused by the newborn child..."*

*"...they ask me for information concerning the health problems my son might have between now and a few years' time, in three or four years from now..."*

In Psychiatry they also distinguish between times when the families come to the clinic, it being possible to make a distinction between the following:

- Before 10 years of age, which is when the problem first arises. The parents come to the clinic feeling extremely frustrated since their child manifests difficulties in relation to their companions and interaction is more complicated. The parents are usually reluctant to visit the clinic for such reasons.

Families usually deny and /or justify the conduct displayed by their child with DS, and are often reluctant to accept treatments with psychotropic drugs.

*"...I see parents that are very angry and very reticent about coming to the clinic. There is a refusal to admit it, as though Down syndrome justified everything that might happen..."*

- Between 12 and 14 years of age, when the problem starts to take root.

A psychic pathology has now become established, like a very marked social inhibition of an obviously affective nature, social phobia of a delirious nature, selective silence, etc. This type of pathology is slow in coming to light in the clinic since the families only resort to this department when other channels have failed. In the survey they stress the fact that a great improvement where this type of pathology is concerned may be due to two factors; early detection and adequate treatment.

- From the age of 16 onwards is when the conduct becomes ingrained and very difficult to treat.

Prepsychotic states, strange behaviours, a sense of shame, denial, etc. start to appear. The families usually deny the magnitude of the problems in their child's behaviour and the psychiatrist has to tell the families things they do not want to hear, since an intense feeling of anxiety emerges. However, treatment in such cases is often very difficult.

*"...looking the other way when faced with certain types of behaviour that might be classified as illnesses would be what the parents do; the parents don't want to get stressed out..."*

## 2. SOCIO-AFFECTIVE DEVELOPMENT

In this section the professionals highlight the families' requests for information in several aspects:

- Social skills: parents are often very demanding in this aspect, since they want the training of their children with DS to be the same in this area as that of a child without DS.

In children without DS, learning social skills is usually a natural acquisition process, with the intervention of the school setting, family, a positive social milieu, friends, etc. Children with DS, however, experience a lengthier acquisition process, in which learning events should be sequenced, worked on at home and fomented within the family.

*"...we have to teach them step by step. They don't learn it easily by seeing the experience of their friends. You have to explain it to them, you have to work on it, do role-playing exercises..."*

- Another reason for families visiting the clinic often refers to the self-esteem of their child with DS, since it is at this age that they usually become aware of their own disability. It is an aspect that is of great concern to their families and they demand information on how to help their children face up to this aspect, how to provide this information and how to promote self-esteem in children with DS.

*"...in self-esteem as well, when going through adolescence is when some of them start to become aware of their own disability... They start to worry a lot at that age about how they can be helped to raise their awareness, to accept their own disability..."*

The professionals also talk about another type of enquiry or request on the part of the families: the need and the right to look after themselves as parents, as people, claiming a time that they feel they are lacking, along with emotional support.

The families demand their need to share their experiences with other parents. Through such groups of parents, the families are able to share their

experiences, release their feelings, enjoy support and have the feeling that they "are not alone" in confronting certain situations.

*"With reference to a group of parents:...the sessions that turn out best are those that deal with one topic, where we are going to talk about the topic from parent to parent..."*

*"..They comment on it themselves, and come out feeling more relaxed: it isn't just happening to me..."*

They also demand the need to have time to themselves to rest. A feeling emerges that they are never going to be able to stop looking after their children, that they don't have enough time, etc... This feeling is shared by many parents, although in each family the feeling and the need are experienced in different ways. In some cases this may be due to a lack of organisation in the household, lack of resources, overprotective relationships with their children...

*"...their own time for themselves, time to rest and relax..."* *"...I exist as well..."*

### 3. SOCIO-ECONOMIC RESOURCES

The group of professionals participating in the Focus Group did not highlight any type of demand referring to the resources they have to offer, possibly because the channels of information chosen by the parents may be different.

### 4. AUTONOMY

The facilities offering recreational and free time activities promote the acquisition of skills that favour autonomy in the children's everyday life. Families demand information from such facilities on how to foment these skills and about the interaction of their children within a group; relations with other children with DS and in groups where they are the only child with a disability.

*"...when out camping, you see children that can get dressed by themselves, that can eat on their own, ....the parents say: at home he doesn't eat like that, at home he doesn't get himself dressed and we have to put his clothes on for him..."*

## 5. EDUCATION

The speech therapist: from this service the families demand:

- Information on language development; they want to know at what age their children with DS will start to speak.
- They consider communication to be fundamental in our society, and therefore the acquisition of the written and spoken language often generates anguish within the family; they ask for information on the skills the child is supposed to have acquired with respect to his or her chronological age.

This department stresses the importance of removing the myth surrounding this aspect: chronological age - appearance of certain skills.

*" ...parents want us to be capable of telling them what age of development their children have reached with their language level..."*

*"... We can give them the information they ask us for ... with a great deal of caution, as there are so many expectations that we are not going to be able to fulfil that make it a risky subject..."*

From the education centres and special support units: in this age group, which ranges from 8 to 16 years of age, there is usually a change in the school approach, an aspect that sows doubts and fears in the minds of the families.

The parents ask for information on whether it is convenient or not to change their children's school, the different types of Special Needs Schools, relations with their schoolmates, the aspects worked on at these Centres...

There are parents that, when faced with a change of school from an Inclusive School to a Special Needs School, see it as a failure, and neglect of their children. They lack information about these education centres. On occasions, once over this initial sensation, the families dispel their doubts and fears as they see obvious progress in their children with DS.

*"...at this age they also worry a lot about the school - if there will be a change of school, if it is a good idea or not...That's when a lot of doubts arise..."*

*"...the ones that come - the parents - at first they come with the feeling of what actually is a special needs school? ...Are we going to work on their reading skills here?"*

## 6. SEXUALITY

The families are starting to feel concerned about the sexuality of their children between the ages of 12 and 14, with the onset of puberty and the changes this brings with it (menstruation, etc.).

This generates a kind of fear: the type of information they should give their children, and how the family itself should go about tackling this aspect of their education.

## 7. SOCIAL INVOLVEMENT

With respect to Leisure, Sports and Free Time Activities, they point out that the demands expressed by the parents are as follows:

- Acquisition of skills that enhance autonomy in their daily lives.
- Interaction of their children with the group, with children of the same age, both with and without a disability.
- Information on when their child is going to acquire a specific skill, learn how to swim, kick, etc. They ask the organisation to advise them of when they can expect their child to acquire such skills. The organisation notes the importance of raising the awareness of the families about the process itself rather than about the chronological age at which a certain skill "should" have emerged.

*"... the parents' main question is: but will my child manage to swim?"  
"...we explain to them that the process is much slower, but the goals are reached in the end..."*

- **CONCLUSIONS**

To sum up the contributions of this first question, we can offer the following conclusions:

- On the part of the families, there is a need for information with respect to the achievement of objectives when working with their children: they need to know and anticipate the moment when these objectives will finally be reached.
- For this reason, the professionals point to a feeling of anguish detected in the families, when their expectations are not met, when the achievement of such objectives and the learning processes go on for a long time.
- The families' sensation that they lack the space to be able to share their experiences with other parents is patently obvious, along with the subsequent relief they feel when they find the time and place to do so.

- **QUESTION NUMBER TWO, ACCORDING TO YOUR PROFESSIONAL EXPERIENCE, WHAT INFORMATION DO YOU CONSIDER FAMILIES OF PEOPLE SUFFERING FROM DOWN SYNDROME REQUIRE?**

We shall analyse the information contributed by the professionals on the needs of the families with reference to the areas recorded in the questionnaires.

### 1. HEALTH:

From the Psychiatry department:

They stress the importance of bringing the world of psychiatry "closer" to the families of people with DS, and the need for it to be considered much like any other visit, in an attempt to take away the myth surrounding it and remove the social taboo implied in going to this type of clinic.

Such activities are aimed at being able to achieve EARLY DETECTION, since it is vital to be able to detect behaviours and problems that are treatable at the beginning but that tend to worsen over time and, when the families finally come to the clinic, are very hard to treat.

The need to remove the myth also surrounding treatments with psychotropic drugs in children and young people with DS, as this group shows a reluctance to use this type of treatment, which can greatly improve behaviours found in these children.

*"...they should have information on the medication that might improve behaviours."*

*"...having to take psychotropic drugs is a real tragedy.., the parents wonder: could it be my fault?"*

By way of information, these professionals draw attention to the fact that one out of every four children in other countries is being treated with psychotropic drugs. However, in Spain this service is still considered to be fairly negative by society in general.

They also refer to the need to work with the dynamics of the family with a member suffering from DS. (Recorded in the socio-affective development section).

*"...comorbidity in all children is very common, and in children with difficulties it is even more so...insofar as there is knowledge on the condition, it is possible to treat it..."*

From the Paediatric department:

They highlight as being essential for families of people with DS the importance of telling them the news in a positive and sensitive way.

The families experience the tiny details charged with great emotion, particularly in moments of specific life events such as the birth of their child with DS. This leads us to the belief that the information we give the families should be given with great care and sensitivity, since the words, gestures and expressions used will be remembered forever more. It is important that the families feel they are not alone.

*"...even though you might talk about the most serious of heart diseases, always do it in a positive way...don't give aseptic information, you need to personalise it, otherwise it wouldn't be fair."*

From this department they think that it is important to give information on the healthcare programme designed for people with DS, and inform them about the genetic aspects of the syndrome, as, many times, the families have the feeling of guilt for what they refer to as "genetic failure".

*"...why have I given my son this defect? ...the families need to be given good genetic information..."*

They point out that the information given to the families should be balanced and without giving any cause for alarm.

## 2. SOCIO-AFFECTIVE DEVELOPMENT

The professionals refer to the families' needs concerning their own affective health as parents and people, and within the family context as well. Some of these needs are set out below:

- The parents of people with DS should be aware of the importance of the family dynamics. Reference is made to the "suffering" of siblings of people with DS (from 6 to 18 years of age), who usually find themselves relegated to second place by the brother or sister with DS.

The parents should understand that it is imperative to have a different type of affective bond with each child and that this should be well established right from the very beginning.

- Within the context of the family, they stress the importance of sharing the responsibility of the education of children with DS between both parents, without delegating all the responsibility to a single individual, which usually turns out to be the mother.
- The professionals coincide with the families in the need to share their experiences with other parents, since there are moments that are charged with a great deal of emotion and when these are shared with other people going through a similar situation, they release feelings and generate a sensation of "not being alone".
- They point out that the changes that emerge during the growth of a person with DS give rise to another emotional shock for the families. They refer to puberty and adolescence in children with DS, a situation that is experienced with great anxiety on the part of the families. The professionals point out that being able to anticipate the information concerning forthcoming changes will dissipate the anxiety, doubts and fears these tend to generate.

*"In relation to puberty: ...information needs to be provided in advance on this change..."*

- **SOCIO-ECONOMIC RESOURCES**

The professionals refer to the families' concern about the resources that will be available to their children with DS once they reach adulthood. The parents point out that they do not want to be a burden on their brothers and sisters, etc. They are worried about what the best type of resource will be when this situation comes around, and what form it should take, i.e. homes, etc.

*"..This is one of their main concerns, even when the child is only a few years old. What will happen when I am no longer around?"*

*"...they are concerned that their siblings feel obliged to take responsibility for them and that such a relationship will not work out ... and they look for alternatives..."*

### 3. AUTONOMY

The professionals tackle this subject from the perspective of the over protectiveness and permissiveness of the parents when faced with certain behaviours, these being aspects that do not favour the acquisition of good autonomy skills in a person suffering from DS.

The professionals note that in those cases in which no work has been done on the autonomy of people with DS, and the parents have indulged certain behaviours, such conduct is perpetuated in later life, making it very difficult to work with them.

The parents should be informed of the importance of fomenting such skills within the context of the family, and from early ages.

The professionals stress the need to provide the parents with this information, since this will favour the acquisition of good autonomy skills.

*"...when they are thirteen years old and don't do anything, they realise...I think it is important for the parents to be given information at all times on the work that can be done in the home..."*

### 4. EDUCATION

The speech therapist:

The professionals stress the importance of the parents knowing certain aspects about the language acquisition process such as:

- Separating the language acquisition process from the chronological age at which specific skills appear.
- Respecting this process and the rhythm of development experienced by the child going through it, along with respect for the idiosyncrasy of each child.
- Fomenting the need of the child to communicate in the home, since there are times when the child does not have to make an effort at home to have its needs satisfied, which may slow down the speech process.

- Providing information on how to stimulate language in the home, with exercises that can be done at home, without triggering a sense of feeling “burdened” or “home therapy”. The aim of these exercises is to reinforce the work done in the classroom.

From the Education centres and special support units: with reference to the first question, the professionals see the need of the families to be given good information and educational guidance.

Information referring to the various different types of schooling available, special needs schools, the convenience of a change of school, etc.

They bring up the subject of the parents’ over protectiveness again, which “slows down” the skills acquisition process.

We should explain to the families that the acquisition processes are much slower and we need to allow them time to go through this process.

## 5. SOCIAL SKILLS

All of the professionals stress the importance of fomenting such skills, for people suffering from DS from early ages included, within the context of the family and in all their activities, with demands being adjusted to the level of skill already acquired by the child with DS.

## 6. SEXUALITY

The family also requires information in this field.

They usually demand supervision on the part of the professionals when their children reach puberty and mix with other children of the same age. Likewise, they also ask about what type of behaviours are found when their children are not under parental supervision.

With respect to the first question, it is patently obvious that the parents see the changes that take place during puberty as a new challenge to be overcome. The professionals propose offering information on such changes, on how to tackle it from the family perspective and being able to “release” the feeling of anxiety it generates in the families.

## 7. SOCIAL INVOLVEMENT

In relation with the first question, the services fomenting social involvement consider it to be important to inform the families about the idiosyncrasies of each child with DS, and the process of acquiring specific skills, while respecting each person's own natural rhythm.

*"In relation to the subject of over protectiveness: ...they should say: we're here and we want to do more..."*

### • CONCLUSIONS

Summing up the contributions made in connection with the second question, the professionals point out that the families need information on the following aspects:

- Being aware of the importance of fomenting social skills, autonomy, etc. from early ages, as well as all the other cognitive skills (language, reading and writing)
- Advancing this type of information to the families, tackling the subject of over protectiveness by the family, and the repercussions this might have on the development of certain skills.
- Bringing the families closer to the world of psychiatry and its potential treatments, slowly being able to eliminate the feeling, espoused by society in general and by the group itself, that this speciality is somehow taboo.

QUESTION NUMBER THREE, ACCORDING TO YOUR PROFESSIONAL EXPERIENCE, WHAT SHOULD THE NEW DVD TOOL BE LIKE TO MAKE IT AS ACCESSIBLE AND COMPLETE AS POSSIBLE?

The contributions of the professionals were as follows:

1. It should use simple, positive language.
2. It should include different testimonies, so as to reflect all the realities faced by people with DS.
3. It should have images that can show how problems can be resolved.
4. It should have home videos that provoke changes of attitude, affective mobility...
5. It should reflect the positive evaluation made by the families of people with DS; it arouses an affective, emotional part, values, appreciating changes and achievements...
6. They should be shown doing different types of activities: sports, games, etc.
7. On the part of the professionals, the ability to show types of stimuli, simple exercises, things to bear in mind when working at home...

## FOCUS GROUP: PROFESSIONALS WORKING WITH PEOPLE WITH DS FROM 18 TO 40 YEARS OF AGE

### PRESENTATION OF THE GROUP

The group is formed by professionals from various fields, such as health, education, and social development, dealing directly with families and people with Down syndrome in this age group.

### ANALYSIS OF THE QUESTIONS

The questions presented to the group were as follows:

1. - From your *experience* of dealing with the families of people with Down syndrome, what, in your opinion, are the needs of such families?
2. - In your everyday work, what is the demand most commonly expressed by these families?
3. - What do you believe would be the most suitable design for this tool to make it most accessible to the families for whom it is meant for?

We shall now identify the main contributions of the group with respect to each question, making a specific endeavour to quote any literal comments that support such ideas.

With reference to the **first question**:

- From **your experience** in dealing with families of people with Down syndrome, what, in your opinion, are the **needs** of such families?

Generally-speaking, we can say that it would be to provide them with adequate guidance, offering them suitable, realistic information on various aspects such as health, education, legal matters, and socio-affective development.

To be more specific, in each of these different fields, the needs detected would be as follows:

### Health:

- Gynaecologist: "...to increase the number of people that attend the clinic and try to provide the safest and most efficient form of contraception - to avoid pregnancy - that will not harm their health and, at the same time, is a method demanding very little involvement on the part of the user, so that there is no need for someone to be constantly checking up on them..."

"...persuading them to have a simple gynaecological check-up is really difficult...if they are often accompanied, it is because of the fear of pregnancy..."

- Neuropsychiatric: "The families need more information on what aging involves in people with DS, and how to distinguish these symptoms from possible mental disorders or neurodegenerative diseases".

### Education

- To implement programmes to stimulate and maintain healthy habits in their children: to encourage their autonomy and self-esteem, to assume responsibilities, to acquire decision-making and social skills (for example: starting and keeping friendships), doing sports on a continual basis, nutrition, leisure activities, etc.
- Helping to speed up the formalities involved in gaining a place in education centres, and encouraging them to stay there for an extended period of time.

- Really adjusting their expectations to their children:
  - "...many times their child is capable of doing much more than they think..."
  - "...they're not at all stupid. This is something that many parents find hard to believe..."
- Avoiding the urge to over-stimulate and over-protect their children and their surrounding environment:
  - "...kids that go to a centre in the morning and then come here from Monday to Friday...we try to tell them to release their child from some of their activities, but they say no, that their child is OK. They find it difficult to understand that it is not a case of capacity but rather of the need for freedom..."
  - "...assuming that their children are already grown up, and, as such, their needs will be different: having friends, being autonomous, being able to get around on their own..."
- Being able to provide for the future of their children when they themselves are no longer around: handicaps, designation of a legal guardian, etc....
- Supporting the work carried out by various professionals within the framework of the family.

### Legal matters

- Supplying information on everything referring to handicap, the law on dependence, resources, etc. Being able to provide for the future of their children when they themselves are no longer around: handicaps, designation of a legal guardian, etc....

### Socio-affective development

- Need of the family to take a rest.
  - "...many families reach ages when they are also very tired and don't know what to do..."

"...it seems that while they are still small, I can leave them with the next-door neighbour and it's all good fun, but when they are that much older it is not..."

- Promoting communication with their children at vital times in the life of the family, for instance, when the family goes through a change in its structure.
  - "...Normally at these ages, if they have brothers and sisters, these leave home and get married, while the disabled child remains behind...they usually express their feelings about their brother or sister getting married, leaving home and 'I'm still here'. This is all very difficult for the parents to explain to their children..."
- The parents being aware that their children may and also should be frustrated.
  - "...sometimes it is not so much a case of them not believing in the capacity of their child, but, poor thing, ...a child without a disability can also fall over and it doesn't mean anything..."

"...I am going to leave him on his own but will go on watching him and if one day something happens that will be the end of it. NO, that's life, it's only normal that something should happen..."

### Sexology:

- Respecting that your child will have behaviours and desires as an adult in relation to other persons.
  - "...I think that some families could eventually come to understand the relationship between two people, but then there is the other family, and that makes it complicated..."

With reference to the second question:

- In your everyday work, what is the demand most commonly expressed by these families?

Generally-speaking, we can say that in terms of quantity, these are fewer than the needs detected by the professionals, although it is true to say that they do coincide when it comes to requesting information and/or guidance in the various different fields: health, education, legal matters, and socio-affective development.

To be specific, in each of these areas, the demands set out are as follows:

### Health

- Gynaecologist: the families usually request sterilisation

### Education:

- Information on educational opportunities after leaving school:

"What will happen after leaving school? Will they receive any more training or should I think about them entering the job market?"

#### Legal matters:

- Being able to provide for the future of their children when they themselves are no longer around: handicaps, designation of a legal guardian, etc.

#### Socio-Affective development

- They also want to guarantee their children's quality of life when they are no longer there.
- Sexology:
  - How should they go about controlling the affective behaviour of their children?

With reference to the third question:

How do you think this tool should be designed for the families, to make it easy to access?

## PROPOSALS FOR THE DESIGN OF THE DVD

- It should combine text and video, with:
  - o Clear, concise, and everyday language that is accessible to all families
  - o Images of people with different levels of Down syndrome (including even the most acute levels)
  - o Images of how kids think and act without the presence of their parents in various different contexts: camps, leisure activities, sports, occupational therapy centres, training centres, schools for special needs, etc.
  - o The involvement of the person watching it, for instance, using open questions: and what do you do? What is your opinion about this?
  - o Block groupings, making it easy to search and use, while endeavouring to group the objectives to be worked on in different areas
  - o Communication being promoted with the professionals

## FOCUS GROUP PROFESSIONALS WORKING WITH THE OVER 40S

### THOSE PRESENT:

Professionals connected with the environment of the residential home (Psychology, Social Workers and carers)  
Professional staff from the Health sector - neurologist.

### NEEDS OF THE FAMILIES AS PERCEIVED BY THE PROFESSIONALS

The professionals take as their starting point the premise that there are two significant types of family reality:

A more modern type of reality, with **younger families** that visit associations or various different organisations

*"to have a current vision plus contact with associations and informed families that share a philosophy of social, occupational and educational integration."*

*"The idea of families that are aware of the fact that with DS it is possible to do many things right from the start constitutes an integrationist philosophy that has amazing results. The level of demand shown by the families is also going to be very high."*

Another type of reality, exhibited by **families with very elderly parents and people suffering from DS**, is seen mainly by professional staff working in residential homes.

*"Another type of reality also requiring a response even though it forms part of a different kind of reality than the one the associations are usually in touch with."*

*"Very elderly relatives, in many cases single parents that cannot take care of their children's needs, adults that never received all the encouragement that is available nowadays ... and thus have different needs."*

The professionals draw attention to the fact that feelings of GRIEF arise in the families (the need to also look after their child), LONELINESS, UNCERTAINTY, (What will happen when I am no longer around?) and GUILT.

*"They are not cared for as well as when they are at home but as I can't look after him... This arouses feelings of guilt. They think there's no place like home and this creates a vicious circle of guilt and necessity."*

*"In some cases the feeling of guilt is so immense that they make demands on professionals for things the parents themselves cannot do or things that they have never done at home."*

They consider that a fundamental need of families with children residing in homes is **TRUST**.

*"We also have to work with the family to make them see that the quality of life in the residential home is very good, that the professionals are well acquainted with the people working there, so that the families can delegate such responsibility without any feelings of guilt and in a state of **TRUST**."*

*"The families see the residential home as taking a step backwards. It is important that they should know the set-up at the home to dispel their fears and see that people with DS can also learn to live outside the family circle (family bubble) by developing strategies that will help them and bring them into contact with new things."*

*"As the family doesn't see this, they aren't aware of it. It is important that they should see it for themselves so that they appreciate it as being a step forward."*

*"The family finds it difficult to accept criticism, - they justify it ... that's here but they don't do it when they are in their own home ... the family find it hard because they see it as interference ... we have to find the right point, where we can say things clearly without offending them."*

They all agree that the families need the **SECURITY** of knowing that when they are no longer around, their children will still be looked after in the same fashion. **INFORMATION** on what their child will be like, who is going to be in charge of them, how they will be looked after. They need to be told about the **ADVANTAGES** of getting away from the family environment (some parents find this very difficult, they have a really hard time because they have hardly ever been separated from their children). Being able to relieve that anxiety is very important.

Relatives of people with DS have two basic fears:

- Of the future in general

*"What will happen to them when I am not around anymore?"*

- Of the handicap issue.

*"There is a broad gap regarding the implications involved. They see it as being something that is generally negative when it is really something that protects people with DS. In their eyes it is a restriction when it really provides their child with security."*

They stress the fact that information should be offered on the benefits that come with declaring a handicap (even though it also implies certain restrictions), especially the protection afforded to their estate for legal purposes.

They all agree that information on **LEGAL** issues is a necessity for the families:

- **LEGAL CAPACITY/INCAPACITY**

## - WILLS

*"The family are really concerned about who will look after them when I am no longer around... and in my opinion, the legal issue is the most important of all because nowadays a person with a disability that is handicapped will be looked after by the institutions when their parents are no longer around - they won't be left roaming the streets. But if they aren't handicapped, they will have a lot of difficulties because they may well lose all their possessions."*

It is really important that the parents receive information from associations and organisations on the legal matter concerned, together with the steps needed to be taken, although the parents find this difficult because of the recognition this entails.

With respect to the subject of homes, there are various types of family reality:

- People with DS that spend weekends at home or pay odd visits to relatives outside the residential home.
- Relatives (parents, siblings...) that visit them in the residential home.
- Receiving supervision from institutions if they do not have any family.

Their needs are also different in these cases. The family's vision is determined by the dynamics, by their family relationship, their past history, the implication of siblings... this also gives shape to the idea the family has of the professional and the flow of communication between them.

*"This does not imply that taking him home means that he is looked after any better or worse ... there are families that can't have them at home but really look after them when they visit the residential home."*

*"Some siblings have felt really overshadowed by their brother or sister with DS."*

*"There are siblings that ask why they haven't got DS... They feel invisible and it doesn't matter what you do, they still feel that way."*

*They also stress the importance of **AFFECTION** and feeling loved (by parents, siblings, relatives) even though they remain in the residential home. This is important and marks their stay at the home. They say the siblings issue is a delicate subject because of how they have received the news or because they feel "obliged" to take on the burden of their brother or sister when their parents die. This is an issue that is always there, either directly or indirectly, and needs to be worked on both within the family setting and by the various different associations.*

*"While their parents are still around, it seems like there is no one else that can look after them as well as they can..."*

*"It's something that should be worked on with the family, getting them involved when they are very young and there are brothers and sisters that behave wonderfully ..."*

*"The associations and organisations attempt to foster the issue concerning the brothers and sisters."*

*"...if their siblings go on being affectionate ... even though they are in the institution, and have settled into their life there for whatever reason, they are still full of affection and for them their brother or sister is really important.... it depends on the individual experience of the family itself."*

*"... There are brothers and sisters that feel under so much pressure to be responsible for their brother or sister when their parents are no longer around... that it is difficult for them to bond naturally. If not, they see it as being something that is imposed on them. You have to give your brother a piggy back ride ... and then as soon as they can, they drop him. It is important to establish bonds with them because it is good for them to love us and for their brothers and sisters to get involved."*

*"... with disabled people it is clear that they are more comfortable staying in the residential home if they feel loved by their family..."*

*The professionals agree that, with family circumstances being different in each case, people with DS that are not looked after properly or that do not receive much affection from their immediate family, develop fantasies that need to be contrasted with reality.*

A discussion arises as to whether it is better to stay at home whenever possible or to stay in an institutional centre. They all agree that the ideal situation is to combine the two, but there are cases where depending on the family dynamics and structure, dual dependence, etc, staying at the residential home is justified as being beneficial. At the centre they have contact with younger people, they also receive affection from the professional staff attending them and sometimes the institution itself can be a catalyst for assuaging the fear of depending on their siblings.

It is important to REMOVE THE MYTH surrounding the residential home, to have a POSITIVE VISION of it, as another stage of development, not just as a last resort or somewhere to park them.

### NEEDS DEMANDED BY THE FAMILIES FROM THE PROFESSIONALS

The demands made by the families depend on age, sex and intellectual level. In girls there is greater PROTECTION because of fear of abuse; in boys, there is more a fear of society.

These fears are also manifested in the way the parents curtail their autonomy because of the risks involved, even preventing them from having an independent life in supervised flats, or from having access to normal jobs. The families think that in a protected environment the risks are reduced.

It is important to work with the families on accompanying their children and supporting them in their attempts to work and gain autonomy. There are latent demands but none that really stand out.

The fear of sexuality also continues in families with people over the age of 40. It would be a good idea to establish a protocol for professional procedures regarding sexuality because the barrier between the information demanded by the children and the position of their parents is not always clear.

*"Many times it is necessary to raise issues with the families because otherwise these are not brought up ...such as sexuality."*

*"They do not even worry about the children...They do not consider venereal diseases, only pregnancies..."*

*"They still have fantasies about having children, and boy or girlfriends..."*

Communication with the families is essential to detect their needs, adjust expectations because sometimes the families ask the professional staff at the centre about things that they do not do at home, or because they are surprised by their behaviour, albeit positive or negative. There are families that are constantly seeking a reasonable amount of information (on cleanliness, health, physical exercise...); others that ask for too much information or indulge their expectations unduly; and others that hardly ask anything at all.

With respect to the health of people with DS, the neurological issue is also very important. The families learn about premature neurological deterioration, and the greater risk of suffering from Alzheimer's. It is important that the family should have INFORMATION on ALZHEIMER'S DISEASE. The information should be contrasted: clear, objective, abundant and real.

It is also imperative to know that, according to epidemiological data, those people that have a close relative with DS have twice as much probability of suffering from Alzheimer's disease for genetic reasons.

The neurologist supplies the following statistical data:

*"From the age of 30, people with DS have lesions on the brain, which doesn't mean to say that they have the disease or that they have dementia. Statistically speaking, out of 106 cases with DS, in the group of 30 to 39-year-olds there were none with dementia (expectations of old age); in the 40 to 49-year-olds there were 16% with dementia; and in*

*a final group of the over 50s, 38% had dementia. This needs to be known."*

Hence, the importance of having competent medical staff that can offer clear information on the early ageing process of people with DS so as to be able to make a DIFFERENTIAL DIAGNOSIS OF MEDICAL PROBLEMS AND PNEUROPSYCHOLOGICAL DISORDERS, as opposed to other illnesses such as depression, or the presence of cognitive impairment. When the family detect symptoms of cognitive deterioration, this is the time to see the specialist. Neither is it necessary to try and give the news as soon as possible because, as the neurologist says, it can only be diagnosed, but there is no cure. The family should know where to go for monitoring and supervision.

## PROPOSALS FOR THE DESIGN OF THE DVD

- The need to show the interaction of people with DS outside their own family, with other children, with monitors, relationships with their peers without being conditioned by their families. To give their families the opportunity of seeing how they behave without the support of the family, and the resources available to them.... because they are astonished at what they are actually capable of doing.
- Testimonies by the children themselves. Letting them talk. Free and direct questions:
  - o How they see themselves with relation to work
  - o How they see themselves in the family
  - o How they think their family see them
  - o Own expectations
- Showing options for adult life: institutions, supervised flats, family life ... according to individual needs. Not only according to level of intelligence, but also with respect to autonomy.
- Showing their life in institutions other than when they are being given assistance, without causing pity... Offering a positive view of the residential homes.
- Showing subsidies, resources. Applying for places and deadlines... Providing information on guaranteed aid when the parents die.
- Talking about innovative experiences from other communities.
- Health - premature ageing.
- Views not only of very elderly families, but also of younger ones.
- Drama as a communicative tool - Performance of "Desde lo invisible" (From the world of the invisible), a play about disabilities.

## FOCUS GROUP FAMILIES WITH CHILDREN OF 0-6 YEARS OF AGE

### POSITIVE ASPECTS HIGHLIGHTED BY FAMILIES AS THE MOTHERS/FATHERS OF A PERSON WITH DOWN SYNDROME

All the families that attended agree that the **experience of having a child with Down syndrome has changed their whole outlook on life**. They have learnt to value other things and to consider that **"there are other ways of living in the world"**. It is interesting and also worth noting that the opinions offered by the families in this light are determined by the reality of each family, such as the profession of the parents, for instance:

*"Perhaps I do value it. Perhaps other things that you used to consider very important, nowadays when something like that happens to you, I think you give it much more importance, you know? Well, that's what I think, that other things may have been much more important to me before, and now because of this, I don't regard them as being so important."*

*"Well, you value other things in my opinion. I don't know how to explain it, you value other things... But what I try to give... maybe the only thing I know how to give him is affection, a great deal of affection. That's what I want to give him - affection, and to make him happy. But priorities - because I treat my son in the same way as my daughter - but this simply means giving him a lot of affection, nothing else. I try to treat him the same, perhaps I don't... (laughter) I don't treat him the same, but I try. But of course, I try to be as fair as possible. But the same values, to make him happy."*

*"For me it really was a great upheaval in one sense. I am a Maths teacher, and so, like it or not, for me having intelligence and the*

*capacity to understand the world is very important for me and I actually work very hard with my students... For me it was essential to go through life being able to understand it, being able to comprehend and giving great value to intellectual issues because of the nature of my job, the subject I teach and also to some extent because of my passionate view on the importance of having a brain to understand the world. So, when L. was born, to tell the truth, the thing that was hardest of all for me was thinking that maybe he wouldn't be able to learn how to read, that perhaps he wouldn't have the brain to be able to understand something that for me seemed so important. And, well... fortunately, I don't know, I believe that God sets things in your path that make you more mature in certain ways and the truth is that when L. was born, it didn't take me long to realise that there are other ways to live your life and that my son is only 16 months old but I have completely changed my outlook. This doesn't mean that I don't value it as much because I think that each person behaves differently and that everybody has to develop their own potential to the utmost, but if you haven't got it, then I think I will be able to accept that not...I have learnt to appreciate that there is more than just one way of being in the world."*

*"...I'm a shutterer and I come from a team of shutterers with 6 people: our parents have retired, and the kids have taken over and me, well, how shall I put it? I can't see Jesús hanging from the eighth floor, mounting a beam in the ceiling. You talk about Maths and I say the same thing because of shuttering".*

*"Your values, your outlook on life changes."*

*One significant aspect, brought up by one of the mothers and which she underlines as being very positive, is **having the living experience of diversity** not only on a personal level and at the level of the immediate family, but also in terms of the extended family. All the other families agree, especially those with other children, and consider that this is a very enriching experience:*

*"Positive aspects of the experience for me? Well, I don't really know how to put it...a bit...this might sound a bit strange but having the*

*living experience of diversity... Let's see if I can explain. It's something we all have with each one of our children, because they're all different...because they're all different, aren't they? But, obviously, when you have a child, you live with a person and above all because you become much more attached to them because they're your own child, with a number of limitations, then it's easier to see the difference, isn't it? And sometimes, the wealth of experience as well, because M. is capable of realising that he is missing the spoon for his yoghurt and he gets up to go and get one and his brothers and sisters don't realise. This might be for any reason, because each spoon has to be in the right place (laughter) but, for instance, it is M. that does these things, not his brothers and sisters, right? So, this thing about... well, the thing about there being a number of different ways to be in the world that you were talking about. I think that is the most positive thing, and I think it is positive as an individual experience and as a collective experience for the family as a group. This brings to mind his grandparents, his grandfathers and grandmothers, and not just the closest members of his family..."*

*"I remember that my mother was really afraid. When M. was born, my mother wasn't living nearby. I found out through my sisters, because, like I said, my mother wasn't here with me throughout the pregnancy and as we knew what M. would be like when he was born, she was, you know, obviously worried about me. Then when M. was born, and in difficult circumstances because he was also premature...and, you know, there were a lot of complications ... it was an emergency caesarean and so on... So my mother was frightened about coming to see her grandson because she didn't know how she was going to react. My sisters were like, but whatever do you mean! You've got to go, don't you even think of not going! Then when my mother came and saw it was a boy, a baby boy even though he only weighed a kilo and a half, and he looked like a bundle of... he was very small, but he was a baby boy, wasn't he? He was a baby boy and, you know, seeing his grandmother exclaim that it's a boy, because obviously, the worries, the fantasies, the stereotypes... and so, I remember it in a very special way, yes."*

*"Mine is still very little, but I'm really pleased for his brothers and sisters. Let's see, now I think it's important for his brothers and sisters to have someone different around, to have the practical experience of diversity in a positive way, I don't know, because for them it's their brother. And I tell them he's got Down syndrome and they look at me as if to say he's got what?"*

*"They establish comparisons as well, and look at so and so and they're like, Mum, when is Manuel going to say proper words? And when is who knows what...? So and so says... So, little by little. And sometimes they get very cross that Manuel can't do it and sometimes they get really cross that Manuel takes advantage of the situation (laughter) and well ... things like that. Or when someone at school says something."*

They also reflect upon the **intensity of every moment, every new phase experienced and they have learnt to appreciate more what it takes to achieve some things** that had never occurred to them before with other children (learning how to walk, talk, etc.). They experience each bit of progress as if it were a huge step forward.

*"It seems like a cliché but this capacity to communicate, which he has had since he was little, isn't shared by any of his brothers and sisters...but I have certainly enjoyed a special form of communication with him right from the beginning."*

*"I think that the thing about rhythm, that having a slower rhythm which makes you have to go at a much slower pace with them, of course, this obviously gives you more time to notice everything, doesn't it? And to realise how difficult it is to learn how to walk..."*

*"... when speaking, I was really amazed at the last meeting..."*

*"...You experience all the different stages more intensely and you savour their achievements much more..."*

*"For me, any little thing he does, is, well, you know!... now that he is starting to crawl around on all fours...it's great!"*

*"You are slightly more aware of what education is all about, you realise the significance of things that you do on a normal basis and that you've even done with your other children, and what the process is like, the steps taken, how difficult it is. There are times when you say it's a miracle that everything works and hangs together like it does..."*

Another positive aspect highlighted by the group and for which there is a consensus is the **social liability** assumed by the families of **making the disability visible** to society, of **having a normal presence** in all spheres of life, just like any other family.

*"Not only is it quite positive that you see, the fact that people see that, you know, you have three children, or five in your case, right? And that you have a child with such and such and that even so, you know..., well, you still travel, you go off on holiday, you spend the whole day rushing round everywhere, and you're still able to laugh and everything, right?"*

*"Yes, that's also true in my case as well - telling the students I have about it, because I think that, particularly for the girls, it is important for them to know that you can have a child with Down syndrome without it being the end of the world, and that you can go on working, you're still the same as ever, you carry on with your life and they can see this is so. I often take him to school so they can see him and I have had some very positive experiences, you know, with difficult children.... For me that aspect of making him visible to society is a very positive aspect."*

*"Yes, the visibility thing, the social side of it, yes, that's right".*

*"As far as I'm concerned, if I can contribute my little grain of sand so that these girls - if any of these girls should at any time during their life find themselves in a situation similar to mine and think that it is possible to have such a child and they don't have to be obliterated, ... then, well, I also feel a bit responsible socially speaking in that respect."*

*"There are many little children that ask me - the neighbours and that do ask me. The mums are like, let him be! And so on... And I say, no let the child ask. The girls in particular are very motherly: What about M.? Why is he so little? Isn't he going to grow any bigger? Of course, it's because he's ill! - No, he isn't ill and then sometimes the mums go - Oh, I'm really sorry, etc, etc - and I'm like, no, no, no, let her go ahead and ask, and then I say, don't worry, whenever you have any doubts, just come and ask, and we can talk about it and..."*

### *NEGATIVE ASPECTS HIGHLIGHTED BY THE FAMILIES AS THE MOTHERS/FATHERS OF A PERSON WITH DOWN SYNDROME AND HOW THESE CAN BE IMPROVED.*

All the families agree that the way they were told the news was not the most adequate, and that the impact and way they received it, along with the feelings they experienced at that time keep coming back and they re-live them over and over again many years later.

They point out that having a human relationship with members of the health sector is important (for this as for everything else). Communication is very important.

They all agree that the way in which they were told the news that their children had Down syndrome was very brusque. At such times the only line of defence open to them is denial, not because they do not believe what the medical staff are telling them, but because accepting it necessarily entails a much longer process. All the families remember WHAT they were told but not WHERE. Each experience is different with respect to the latter: in private, in the corridor, to only one partner, diagnosis before the birth... but what really penetrates is WHAT they are told and HOW.

Also important is having the ability as a parent to reject opinions offered by other medical staff and comments from people outside the profession.

*"It's the way they tell you..."*

*"Before confirming the diagnosis, the paediatrician told me: If I make a mistake and he hasn't got Down syndrome, that will be good news for you."*

*"The way they tell you the news should refer to the patient and not the condition... we'll see how he develops, he's going to have these characteristics and difficulties and these positive aspects... and What is going to happen?... it's not necessary to use very specialised language ... he's going to have these difficulties but don't worry because we'll see how we go."*

*"The doctor told me: - your son has Down syndrome, and my question was - how do you know?"*

*He said - let's see, what job do you do?*

*- I'm a shutterer, I reply.*

*- And you can see when a beam is badly made, isn't that so? Well, I'm a doctor and I'm telling you that your son has Down syndrome."*

*"The truth is that I couldn't believe it until the tests confirmed it because the doctor was a real brute."*

*"The worst thing is the uncertainty until it is confirmed. The doctor said, we are going to carry out some tests but if it turns out that he hasn't got Down syndrome, (although I think he has) we will hold a party and have some champagne to celebrate."*

*"The doctor told me that even if he hadn't got any malformations then, he definitely would have later on."*

Even when faced with personal decisions such as whether to go ahead with a pregnancy after an antenatal diagnosis of Down syndrome, one family comments on the opinions voiced by the medical staff. As a way of dealing with this, they all agree that TRAINING in COMMUNICATIVE SKILLS would be the most important.

*"If I wasn't intending to have an abortion, what was I having an amniocentesis for?"*

*"Generally-speaking, people that deal with other people have to receive training, and if you have a natural talent for this, ... but training does exist, and in this respect in the medical profession (as in everything) they have to be prepared to constantly give "bad news", ...*

*They have included a subject on communication in Medicine and it's about time too! Because in something as elementary as that there is a real lack."*

They emphasise the support of friends from the very beginning but say that the family generally find it much more difficult to accept it.

*"Support offered by friends ... the family were biding their time more, waiting to see what would happen. They seem more reserved, more at a loss about what to do."*

*"Support comes from friends, family and professionals. Also from the Foundation, but there is not so much from the medical staff."*

*"Support from real friends is extremely important, from family too, but they look at you as if to say, poor thing, just look what's happened to you, because it's more difficult for them to accept it."*

This lack of EMPATHY in communication between the medical staff and the family of people with Down syndrome is also maintained afterwards in the various visits to the paediatrician.

*"He just sits there ... expressing surprise at all the progress made, as if he didn't believe everything they were learning."*

*"I suppose it is their way of showing they are pleased about such achievements and their way of offering encouragement ... although it is not always the most suitable."*

After the initial moments of distress upon receiving the news, the families do in fact agree that the hospital informed them about the Foundation and put them in contact with a nurse that had a child with Down syndrome, although such a visit is not included in the usual protocol but simply because she is a member of staff there.

*"They refer you to the Down Foundation and from then on the information dries up; after that, I was on my own."*

Another topic is the information you need to know. The uncertainty in the face of the unknown is tremendous. The family is in great need of more and more information, albeit positive or negative, that is both clear and plain. Normally, they obtain this information through other families, or even from the Internet.

The families point to another period of time that is very negative and this is the schooling process and the report and assessment drawn up by the IASS (the Social Services Department of Aragon).

*"This has to be seen as a one-day assessment, a tool that has its faults ... but it shouldn't be taken as a photograph of our son. That much needs to be clear."*

The families state the need for communication between the various professionals, from the teachers and professional staff working at the Foundation.

*"In the end it depends on the goodwill of the person concerned..."*

*"But it shouldn't be linked to a particular person, it should be part and parcel of the way things are done, a collaborative effort because of the understanding that exists amongst the professionals, without the family having to act as courier."*

They also draw attention to a feeling of uncertainty and the lack of information concerning the choice of school (Special Needs or Inclusive School), and ignorance about the dynamics of the centre, its resources and educational approach. It is important to make contact with the Parents' Association to find out information and make it clear that children with Down syndrome are not the only ones with difficulties. Over the course of time the families also become sources of information and a resource we can all fall back on.

*"There is tremendous pressure from society for your son to be the best and the most handsome."*

## PROPOSALS FOR THE DESIGN OF THE DVD

It should:

- Be able to help "eliminate fears".
- Offer the possibility of receiving information for those that need it because there are families that demand general information from the moment of the birth. A general overview of all the stages to help rid them of their fears that is not too detailed but certainly sufficient to banish myths. However, there are other families that do not want to go too far and prefer to live on a day to day basis.
- Portray a lot of children with DS, of different ages and realities, so that we can see that they are all different, and that furthermore they appear to have more similarities with their own relatives than with others like themselves.
- Convey a non-idealised image of reality: "normality is a lie".

## FOCUS GROUP: PARENTS OF CHILDREN WITH DOWN SYNDROME FROM 6 TO 18 YEARS OF AGE

### GROUP PRESENTATION

The group is formed by parents of children with Down syndrome ranging from six to eighteen years of age.

### ANALYSIS OF THE QUESTIONS

The questions put to the group were as follows:

1. - What positive aspects would you highlight in your experience as the mother or father of a person with Down syndrome?
2. - What negative aspects would you highlight in your experience as the mother or father of a person with Down syndrome?
3. - What do you think would be the most suitable **design** for this tool?

We shall now identify the main contributions of the group with respect to each question, making a specific endeavour to quote any literal comments that support such ideas.

With reference to the **first question**:

- What positive aspects would you highlight in your experience as the mother or father of a person with Down syndrome?

1. - Opening your eyes to things you weren't so aware of before.

"...the need to find a society that was more open and rather different from the one we had known before..."

"...to feel obliged to confront something we probably didn't really visualise or not to such an extent, being aware of the diversity of men, of society..."

"..you open up your mind..."

"...it makes us question the values, the education we've received and that we've given all our children..."

2.- Learning how to appreciate other things, or the same things in a different way, we take importance away from it, maybe society pushes you in that direction and it is easy to see yourself moving in that wagon.

"...you appreciate life much more..."

"...the things you achieve make you feel satisfied..."

3. - You positively appreciate their way of looking at life and that helps you to see it differently as well.

"...their affection, simplicity, spontaneity... they are simple and very predictable, even though they have their moments of naughtiness, their own resources but, amongst other things, they show you how you to appreciate the effort put into each action like walking, speaking, reading,...."

"...things take a lot of effort and follow a process towards maturity and that can be applied to everything ..."

"...the love my daughter showers on anything, people, plants, animals..."

#### 4. - Meeting other parents in a similar situation

"...you see you're not alone..."

"...you see that such big problems, problems that are so big, are not so big ..."

"...you get much more involved, you have to consider things to a much greater extent with our children: the future, what type of life we want for him, what type of education..."

In relation to the second question:

What negative aspects would you highlight in your experience as the mother or father of a person with Down syndrome?

#### 1. - The negative experience at various important life events:

##### Birth:

"...the news, accepting it, slowly overcoming the fact that it is a baby with difficulties and that we have to take care of it because it's our child - it is very hard during the first few months..."

"...it is tough, especially when they are born with a problem..."

Education:

"...where you take it, what to do, what not to do, talking to some people, talking to others..."

"...who educates the teachers?"

"...curricular development has to be individual for each one..."

2. - **Loss of personal autonomy**, which has an effect on the individual, the couple, and also on brothers and sisters.

"...you can love your child very much, but your life feels much more restricted. It loses a certain amount of autonomy that is very important in relation to the rest of the people and their everyday life..."

"...we have our ups and downs ...I sometimes get depressed ...I worry about their happiness, their future. it hurts me to think about how all of this might affect them..."

"...Carer syndrome: we don't have a proper life and this can be seen at all levels...your life revolves around them, I never found the moment to have a second child,... the day ends and you're worn out,... you don't know where the limit is and all this affects you psychologically ..."

"...it complicates your life as a couple, you can sometimes feel incredible depths of loneliness, even when you love your children and partner so much..."

"...we think what a terrible thing I've done to his or her brothers and sisters, the traditional family model has shattered into pieces..."

"...nobody thinks about the families: at an institutional level, and doctors, they devote all their attention to the person with Down syndrome. What happens after Early Attention? Our children don't have their Down syndrome erased, do they?"

3. - **Society**, once we've adapted ourselves to our children we have to cope with:

- Unfortunate comments:

"...I'm sorry..."

"...you're going to have a child all your life..."

"...you'll see, they're a bundle of joy, how lucky you are..."

"...they only go to homes that can really help them thrive..."

"...you have won the lottery, actually we have won the lottery..."

- Unfortunate glances

"...they might not say anything to you, but they look at you and sometimes, looks can hurt so much more..."

- repeating the same story over and over again, the same appraisals, going to a lot of places...

- Integration in society

"...society moves at a pace that is completely out of step with our children's rhythm. How can we adapt the rhythm of a child to the rhythm of the society they live in?"

"...what leisure options does society offer our children? It's not prepared for it..."

"...I see full integration as being very complicated - partial integration at most..."

## PROPOSALS FOR THE DESIGN OF THE DVD

- It has to be realistic (both positively and negatively) and valid for the families
- Optimistic line
- Preferably visual: where you can see images ranging from babies and children to adults
- In each age group, select points or strategic moments and formulate possible questions and possible (plural) answers to such questions.
- Facilitate awareness of the world (your child is part of society: he or she doesn't only relate to family and friends)

## FOCUS GROUP PARENTS OF ADULTS WITH DOWN SYNDROME

### COMPOSITION OF GROUP:

Both mothers and fathers took part, with each family being represented by only one member, save in the case of two married couples. The ages of the children ranged from 20 to 33 years old. We were unable to involve parents with children that were older than this. This was interpreted as being due to the fact that such parents were advanced in their years and not in condition to attend the meeting.

### SUMMARY OF THE RESPONSES GIVEN

It should be pointed out that, although the first question to be asked refers to what positive aspects they can highlight from their experience as the father/mother of a person with DS, they start by pointing out the negative aspects and/or the "complaints" they have. Therefore, the feelings of the group will be respected and we shall start by discussing the negative aspects.

With respect to the subject of **health**, they highlight the fact that there has been a lack of information and coordination amongst the various members of the medical profession.

*"Doctors are not trained to look after these children or their families."*

*"Doctors do not have the necessary training to treat these children. They are somewhat disorientated and blame everything on DS rather than trying to treat the patient."*

*"It is necessary to have medical advice. It is not a case of being treated badly. They treat us well but we feel disorientated."*

Neither do they recall how they were told the **news** when their children were born, but they all say there is room for improvement.

*"My experience when my child was born was terrible and this is despite the fact that I am directly involved as I work in a health centre. They aren't trained to give the news of the birth of a baby with DS. Now they are more careful. They try to make sure both parents are there, in the presence of their child... Now they are aware of the importance of such details. The birth of my daughter has been a help."*

*"After the initial "blow" - they just blurt it out without smoothing the way at all."*

With respect to the comments referring to **socio-affective development** first of all, we draw attention to those indicating acceptance of the fact:

*"From my point of view, the problems that used to seem so daunting, after the birth of my daughter with DS, these things were no longer important, with other things taking over. It changes your life. In many ways we are just like any other family but in others we are very different".*

*"You have to adapt to your child and not the other way around (as in the case of other children)."*

*"My experience hasn't been entirely bad. I mean, from the moment your daughter is born with DS, which is unexpected, the experience is not pleasant, you just "swallow" each stage as it comes, ...you don't accept it either in one year or in two, you accept it at each stage you have to go through."*

*"You never really accept it."*

Another aspect considered to be negative is *"the amount of dedication required, which is tremendous."*

Other topics are also mentioned: these refer to the extended family and reveal a certain sense of a lack of understanding:

*"The whole family were very supportive at the birth, but later on..."*

*"We were on our own when she was born. Then, even though the family support you, they gradually leave you alone. In one communion ceremony we went to, my daughter, who is 28 years old, was completely on her own."*

Many participants agree and share this opinion.

Within the family network there is one aspect they all agree on: the case of the **siblings**. They all agree that they have tried to prevent the brother or sister with DS from becoming a problem for the other sibling(s), or that they should feel "responsible" for them.

*"It worried me greatly that my daughter with Down syndrome's sister should not feel that she was a burden."*

*"I have tried to make sure that each one had her own life."*

*"She couldn't go out with her friends because she wanted to stay with her sister, until I told her not to."*

A reference is also made, albeit in passing, to the subject of the **couple**:

*A doctor once told us: "you are really obsessed with your son when what you should really be doing is looking after yourselves."*

*A good piece of advice is "if the parents look after themselves, they can take care of their child."*

Another subject of concern is that of the **future**:

*"We keep them inside a "glass cabinet" and that isn't good either because one day we won't be there."*

Why do you keep them inside a bubble? (question posed by the moderator)

Fear (most of the participants agree)

With reference to the subject of **education** they all agree that the law on integration was very positive:

*"The law on integration was very important at the time: it was a very significant step at that time.... My experience was that when we applied for a place at the school she was eligible for, she wasn't admitted. That doesn't happen nowadays."*

However, they also agree on the difficulties they have encountered:

*They talk about the gap that exists with schoolmates at the inclusive school and when they are left on their own. Many say that their children have stopped being happy about going to school, and no longer have any friends, or go to birthday parties. It is a difficult experience both for the children and for their parents.*

*"Integration comes to an end - that's the difficult thing."*

*"We've all had this experience as parents."*

*"The problem of inclusion is that we haven't understood it properly. It was thought to be a question of knowledge but it isn't.... There needs to be an increase in social integration. There aren't enough resources devoted to it."*

*"Integration is very positive for schoolmates because they are in contact with people with a disability and learn how to treat them."*

There is a discussion on the **social resources** that are available, with people agreeing that:

*"In Spain we have very little support."*

*"In other regions of Spain the social situation is better."*

*"Politicians aren't interested in these kids, because they don't vote."*

*"Administrations are driven by the force of the associations and the parents behind these. We need to put forward projects that have been well prepared."*

One possible explanation they offer for this situation is:

*"If we unite, we can do a lot more."*

*"We don't join together, and have very little strength."*

*"The problem is that we have been extremely divided. In Zaragoza when the Asociación Down Aragón (Aragonese Down Syndrome Association) was set up, another one was being created at the same time, and then the DS Association itself splintered. Scattering our strength is negative. We are a lot better off now than 20/25 years ago".*

They all stress the recent **Law on dependency** as being of paramount importance:

*"We now have important support in the law on dependency, our children are well defended ....because of the law."*

*"If they can't be looked after at home, they are protected by the law."*

The **handicap** business causes some apprehension. This is a compulsory requirement for many things when the children reach the age of majority:

*"As parents we find it difficult to label our disabled children as handicapped. It is not a very suitable term and seems to cancel out*

*the person concerned. We need to think that the handicap protects the person with a disability."*

*"If they are handicapped, the law protects them. Their legal guardians have to submit a kind of statement of account to the judge on a regular basis."*

They think it is difficult for them to achieve a state of **social inclusion**.

*"We are living in a society that is not prepared to welcome them into its fold."*

They also feel that people make comments about them or look at them in a strange way, and this is really painful for the parents. In spite of this, everyone agrees that:

*"We have to help our children to go out more and mix with other people."*

The subject of **sexuality** is of great concern to all the participants, as their children are starting to display signs of sexual behaviour. Generally-speaking, this is a subject that frightens the parents as they don't know how to act:

*"Now I find the subject of sexuality worrying because she seems to be very 'forward'."*

*"I am worried about what will happen but I am also concerned that I cannot eliminate this facet of her character. People with DS are sexual beings just like everyone else."*

*"They have the same tendencies as all the rest of us..."*

*"My daughter is in love... and I don't think she is happy like she is at the moment - she wants more."*

*"I would like to be able to explain sexuality to my daughter but I don't know how to, because I feel so frightened that I get a mental block."*

The families also point out that they are **afraid** for their children:

*"We are worried that our daughters might be abused. Daughters cause more concern than sons although we can't forget our sons..."*

*"My daughter could be more independent if it weren't for my fear that she might suffer 'abuse' and so I don't let her go out on her own."*

*"There is greater concern about these children living with a partner because of their DS. This does not happen with other children."*

The importance of **training in this aspect** is shown to be relevant.

*"The families need training and advice, as we need to get involved just like the professionals."*

*"The important thing is that, like them, we should also receive training as parents."*

*"I have assumed this responsibility all by myself. I wouldn't like anything to happen to me and the matter to remain unresolved..."*

*"I have doubts about whether my daughter has the capacity to understand the type of sexual education you are talking about."*

*"We never used to think they were capable of taking part in an occupational therapy workshop and doing lots of things before, either. And it's the same thing with the subject of sexuality too. It has to be offered to them and slowly they will acquire this type of training even though we have to insist much more. Even though there might be some that cannot be included, that is not a reason for abandoning the idea."*

They also request more information on **contraceptive methods**:

*"The idea of having her tubes tied frightens us because it requires an operation and having an anaesthetic is possibly a very big step to take."*

There are doubts about whether sterilisation is "compulsory" in the case of attending a residential home.

With respect to the subject of **parent training**, this comment, made by one of the participants, is striking:

*"Within 20 years, they will laugh at us because they will think we are really behind the times. I want information and I want to learn how to teach my daughter. We need resources and money."*

After summarising everything that has been said previously, the moderator proposes that they should attempt to extract the positive things from their experience as parents of a person with DS, although she also recognises the fact that it is normal that they should mention the negative side to get it off their chest. Within the most striking aspects are the following:

- *The situation has evolved positively and has afforded us a great deal of satisfaction*
- *The triumphs experienced are celebrated much more*
- *The child is the joy of the family*
- *Everyone loves them tremendously*
- *We have given them a lot of attention but the result has been very fruitful.....they make us feel more alive*
- *They change our scale of values. It is thanks to them that we have developed a different level of sensitivity.*

## PROPOSALS FOR THE DESIGN OF THE DVD

We then move on to the third and final question: WHAT WOULD YOU LIKE THE DVD TO BE LIKE? WHAT MESSAGE WOULD YOU LIKE IT TO CONVEY? On this matter there is a moment of silence and doubt, although they all finally agree on the following points:

- *They need more and better training. They are capable of learning a great many things*
- *We should not set limits for them - they should do that themselves*
- *Breaking the mould of the parents, since we are too protective. This overprotection should be avoided. We close up because we are offended by comments made by members of the family or by people in general. We protect them to prevent them from suffering like us. Society needs to know that those things are 'hurtful' to us.*
- *We need to take the drama out of the situation. Having a child with DS is a problem but there are lots of things that are worse. Little by little it can be seen that progress is being made*
- *We all wish the best for our children*
- *They are at great risk of contracting illness... It is very important to be very careful about changes made to their environment because this can have a tremendous effect on them. We have to remain alert in anticipation...*
- *It is also important to be able to share with other parents. This is very gratifying*

Everyone agrees to transmit a realistic picture of the situation, which is neither very positive nor very negative.

## OBSERVATIONS/COMMENTS

Throughout the conversation they express the feeling they have of being the ones that are opening up doors and that things have changed greatly in the past few years:

*"The mentality of the parents of the youngest children is different because they have previously acquired rights, early attention, etc..."*

*"Our reality is very different to that of the young parents."*

*"Things have changed a lot since the birth of my daughter, who is 21 years old. The association has grown considerably."*

A final thought for reflection is the following:

*"With the training they have received ... we have created expectations in our children and now we have to supply the answers."*

They feel that they have to go on opening doors to achieve a great many things that are still lacking, such as being able to lead an independent life, supervised apartments, etc.

The comment made by a father that *"there are many children with DS that have finished a degree"*, provokes a few laughs and doubts about whether there have really been that many. They all coincide in the fact that this is not really what they want for their children.

## FOCUS GROUP YOUNGSTERS AND ADULTS WITH DOWN SYNDROME

### COMPOSITION OF THE GROUP.

The group is formed by 15 boys and girls with Down syndrome, between 21 and 39 years of age, all of whom are beneficiaries of the Down Foundation and belong to the newspaper workshop.

### WHAT IS A PERSON WITH DOWN SYNDROME LIKE?

Down syndrome is associated with general disability and sufferers compare themselves with people in wheelchairs or with another type of difficulty. Everybody recognises the characteristic physical features of Down syndrome, but they find it hard to identify other types of features associated with the condition. Most people accept that they have Down syndrome (this is an issue that is worked on at the Foundation with beneficiaries), although some of them have doubts and generally speak in the third person. On the whole they tend to minimise the difficulties experienced by people with Down syndrome, stressing all their abilities, and insisting that they can lead a normal life and do what everyone else does.

*There's nothing wrong, everyone has their own difficulties  
There are different kinds of disability  
We have to be happy with the way we are now, there's nothing wrong,  
I am like this  
They can take part in many activities  
When I was little, my mother used to tell my brother that I would be  
slow at running and jumping, there's nothing wrong, when she grows a  
bit more she'll be able to run, she'll be able to jump, ride a bike, be  
autonomous enough to go to many places, meet new people, do plenty  
of things*

*She's a normal person who can assume control of her life.  
 We sometimes find it difficult to talk.  
 It is important to have a job, classes, and parents.  
 Some of them need plenty of help, while some only need help to learn.  
 I get help from my brothers and sisters. They found the Foundation.  
 When I see Down syndrome people, I recognise them because they have special features.  
 I have a friend who has Down syndrome and looks after her parents and takes care of the house - she's in charge of everything.  
 It's very easy to spot in the face.*

*When I was little I was taken to the Down Foundation but I don't know what they did.  
 When I was little I used to do early stimulation, which consists of games you have to repeat lots of times and say words and repeat and sing and so on  
 I see stuff about Down syndrome on TV, I see physical features but they have jobs, in each job they're the ones that do the most, there's a couple who get married, have a flat and a kid, permanent contracts, they're happy and they have a good time. There is a commercial of a petrol station and a boy with Down syndrome talking to the customer. It's a boy with Down syndrome. There's also a film with an actor with Down syndrome who learns the dialogues and is very nice and speaks very well and I'm very similar to him.  
 I saw a film of a boy with Down syndrome that cried and asked his sister to please stay with him. It was pretty strong stuff but I liked it.  
 We were born this way and we will always have it, it won't go away, it's going to continue (we have to keep going).  
 I think I haven't got Down syndrome, my mates have got it, but I don't know.  
 On the whole, all the parents and teachers are happy and proud of us.  
 We are normal people, just like other people, like other disabled people.  
 We have feelings and thoughts.  
 It takes a bit more to learn things and it's hard for some to walk and move.  
 Some also find it hard to speak so they have lessons.*

## WHO HAVE YOU RECEIVED INFORMATION FROM?

Many of them generally say they have not received any information or at least they cannot remember having done so. They also say they would like to have more information and have better explanations about what the Down syndrome consist of.

*My parents and teachers*

*My mother. She stimulated me with games using colours; she played records to me; she sang a lot of things to me; she made a huge effort. My mother said I had Down syndrome but she didn't explain anything to me.*

*They didn't explain anything to me. I didn't have Down syndrome originally and now I know that I do have it.*

*I never received any information and nobody's ever told me anything. I know I've got Down syndrome because I know. I've never asked, I have a bit of curiosity.*

*Nobody has ever told me I have Down syndrome.*

*My parents told me I have Down syndrome and that's why I find it a bit hard to write an essay or do Maths or numbers.*

## SUPPORT YOU NEEDED DURING SCHOOL AGE

Some of them stress the fact that they didn't get enough support during their school days. On one hand they demand more support from teachers to understand content and acquire skills, both individually (outside class) and within the dynamics of the classroom. On the other hand, they demand more social support because they point out that they often had problems with their school mates (they laughed, they hurt me...) and they felt insecure. In some cases they said they had been excluded from their school and they had been sent to special needs institutions because they failed to reach the prescribed objectives, which made them feel disconcerted because they considered their school to be part of them and they felt bit "neglected".

*I was one of the teacher's favourites; I was a good student and got the best marks. My parents were glad to see me mixing with people.*

*Some classmates liked me and some didn't because they caused me a lot of bother, they beat me up, they scratched my face and I had a big fight. A friend of mine died, I had a tough time and I felt very bad, I wanted to commit suicide and I didn't have much support.*

*Secondary school teachers didn't give me much support, they didn't take me out of class very much and I didn't work much, I only listened but sometimes I understood and sometimes I didn't.*

*My parents supported me so I could speak and walk better and everything else.*

*Once when they wouldn't help me untie the knot in my dressing gown I cut it with the scissors. Sometimes I got punished because they didn't understand what I was doing.*

*Once I got lost because I didn't know where the class was and I was too embarrassed to ask. I was afraid of the boys because they came after me and took my stuff, I wanted to defend myself, I told my mates and the teachers but because I said it so many times he wouldn't take any notice of me and then he talked to my parents about it.*

*My teachers helped me to read, to calculate and stuff using more childish tasks. Later I learned things about work and how to go on the bus on my own. I have received support. After that I learnt how to cook, wash up, get the clothes washed and everything about keeping the house tidy. The teachers helped me a lot.*

*My parents helped me a lot; I concentrated more at home than at school.*

*When I was at school I had some good friends but teachers didn't treat me properly because they criticised me - "this boy doesn't work well" - and they got rid of me because they didn't want me to carry on because they know I have Down syndrome and they said it wasn't right for me. My mother told me I wasn't ever going to go back there.*

*The same thing happened to me and I don't think it is fair because they told me I couldn't stay there anymore and that made me feel bad because I remember them and I wanted to continue.*

*They taught me the value of friendship and companionship and how to mix with other people.*

*My parents and teachers should have supported me more. My parents got cross with me because I cheated in exams.*

## WHAT WOULD YOU LIKE TO HAVE SUPPORT WITH?

The main issues in which they demand more support and information are:

- **Sexuality:** they demand information, to be able to talk about it naturally with their parents, and moral support accepting their potential partner and the possibility of having kids.
- **Becoming independent:** they consider they would need continuous support to acquire a house, administrate their money and carry out transactions.
- **Work:** they demand the means to enable them to continue their development, to keep informed about potential offers of employment and support for their occupational integration in the job itself.
- **Education:** they express their wish to continue their development to acquire better reading and writing competence and improve their general knowledge.
- **Relations and social skills:** some highlight their difficulties in making new friends and maintaining such relationships. They think that we (the associations) can help them with this by organising activities related to leisure and free time and social skill development programs.

*Regarding the sexuality issue. I want to know things about development. I've talked about this with my father and my brother and they support me, but I've told my mother plenty of times and she doesn't understand. She should support me more. And talk to me. We could also do it at the Foundation.*

*My mother should understand everything and tell me good and bad things. I want to meet someone me and my mother both like.*

*I want to have children but having Down syndrome I don't know if I could have children, a husband, etc. Maybe my partner won't like it if I have*

*Down syndrome if he doesn't have it. My partner could help me with chores around the house, the kids and so on. Support consists of information, help, etc. My mother doesn't want to know anything about that.*

*I would like support on the issue of having a partner and I want the Foundation to provide me with information on everything in general. To become independent I would need help administrating my money and expenses.*

*I would like more support to become independent and manage to live on my own. They have to help me improve and do better so I can work on my own projects and achieve my independence (getting a flat, getting a job). There always has to be help available. I also need help from my parents and my girlfriend's parents to pay for the wedding.*

*I would need support with work, more information about the jobs I can do. A job I can do by myself and to be a bit autonomous. I would like to have more practice and more possibilities. My parents have supported me in preparing for the competitive examinations.*

*I want to work and continue with my career, working in an assembly plant.*

*I would like to be able to go on studying to be able to write well and read and have more culture. The Foundation should have more classes and make them easier.*

*I need more support on friendship, I'd like to mix with more people and meet new people. Sometimes I'm shy and I find it hard to introduce myself to people.*

## PROPOSALS FOR THE DESIGN OF THE DVD:

- *Young people and adults have to appear working and explaining what their job consists of. Very different kinds of jobs.*
- *Images and information on occupational workshops.*
- *Us giving our opinions so that our parents can find out what we think.*
- *Explanation of why a person has Down syndrome*
- *Importance for Down syndrome people of mixing with other people, going out, being autonomous.*
- *Down syndrome youngsters who live in supervised flats should be included.*
- *Talking about couples, about parents having to respect and help their children with this issue.*
- *Our parents have to love us as we are.*
- *The importance of our being useful people - to achieve this they have to give us autonomy.*
- *Grandmothers have to let their grandchildren do things, get the bus and stuff.*
- *They have to let us watch movies and not send us to bed when explicit sex scenes appear.*
- *They have to treat Down syndrome kids well because they have to be proud that they are their children.*
- *They have to appear doing all the activities we're good at.*
- *Our classmates shouldn't mistreat us and teachers have to stop them from laughing or making fun of us, etc.*
- *Dressed like modern youngsters and adults.*

## FOCUS GROUP CONCLUSIONS

To complete this dossier, we think it would be interesting to offer some reflections on the needs that have emerged in the focus groups for all ages, including both those relating to the families themselves and also to the professionals:

- The need for good communication between professionals and families, particularly at times of crucial importance. The birth is a key moment and hence the importance of its notification. It is amazing how all the families recall this moment no matter how much time has gone by.
- The need for coordination between the various professionals, a point that is mentioned by both professionals and families. In the case of the families, various different messages/guidelines are received, which leads to a considerable amount of confusion.
- The need for specialised and updated training to improve the attention given to people with DS and their families.
- The need to accompany the family throughout the entire life cycle, especially at times of changes in their development (puberty, adolescence, adulthood, etc.) or of changes in their environment (schooling, starting at vocational training centres, etc.)
- The need for the families to share their experience with other families. Some of them have had this experience for the first time in these particular groups, while others already belong to groups of parents that meet up every now and then
- The need (and the right) to take care of themselves as parents. Also relevant is the importance of the attention given to the child's brothers and sisters, since they sometimes suffer the consequences of having a brother/sister with DS

- The need to be aware of the evolution and development typical of DS, respecting the peculiarities of each person, so as to adjust their expectations, and demand only what they are capable of giving, and avoid making comparisons, etc
- The need for information and training on sexual issues is a particularly difficult subject
- The need to foster communication between parents and children with Down syndrome. In the group of adults with DS, we would like to stress the fact that they do not have a good explanation of what DS really entails. We consider it essential to make a note to improve this aspect and to refer to it specifically on the DVD.

Apart from the needs mentioned above, we would also like to record the feelings that emerge during the families' interventions, which are as follows:

- Guilt
- Anguish
- Loneliness
- Lack of understanding
- Fear

However, not all of these feelings are "negative". There is also:

- Satisfaction
- Joy

As a final reflection, we also consider it interesting to record the idea conveyed by the families about the difficulty of their inclusion in society since they believe it is not prepared for disabled people.

We would like to finish by quoting Maria, a participant in the group of adults with DS:

"They have to love us as we are."



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