

Development of personal and social autonomy in teenagers and young adults with Down Syndrome: an empirical study on self-representations in family relationships

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Abstract

This study aimed to investigate self-representations within the family and their effects on the development of adaptive skills in terms of personal and social autonomy. The target was a group of teenagers and young adults with Down Syndrome (DS), compared with a group of non-disabled individuals. The purposes of this study were: 1) to show a relationship between the development of autonomy during adolescence and the perceptions of feelings and attitudes experienced within the family; 2) to identify a link between a) family relationships which are more oriented towards recognizing the maturation processes with the goal of the autonomy of adolescents with DS, and b) the building of adequate self-representations with positive effects on personal and social adaptation. The study sample was composed of 170 adolescents and young adults, 85 of whom have DS. The instruments employed were the Vineland Adaptive Behavior Scale - Survey Form (VABS), which measures the level of Adaptive Behavior by three domains (Communication, Daily Living and Socialization), and the Family Relations Test: Children's Version (FRTC), which assesses the feelings

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that the subject expresses and receives within the family.

The data analysis showed that while all family members influence the level of autonomy in typically developing persons, individuals with DS are significantly influenced by their mothers. The results are discussed taking into account other relevant research, and the possible implications for implementing prevention programs, as well as parenting and development support strategies.

Keywords: Autonomy; Family relationships; Down Syndrome.

1. Introduction

The achievement of autonomy is a developmental process which starts from early childhood. During the first years of life, children experience, mostly within their own family, the pleasure of growing up and learning, as well as confidence in the autonomy of their skills, which are more compromised in individuals with intellectual disabilities (Zambon Hobart, 1996, p. 30). Autonomy, indeed, is essential for self-confidence, self-esteem, social integration and a good quality of life. This is true also for children and adolescents with intellectual disabilities.

More particularly, the perception of their role in society and the role that other people give to them is an important element in the process of self-knowledge. The role is the link between the individual and society and it regulates every single relationship. As a result, in the living environment there is no social integration without a defined role, and people who are not given any social role are also deprived of the ability to recognize the role of others (Pfanner & Marcheschi, 2005). Such ability is very important for social integration (Montobbio & Lepri, 2000).

To this end, it is interesting to observe the role of adolescents with Down Syndrome (hereover DS) within their family, and their reaction to this given role. Family is thus a fundamental and stable support for personal autonomy and social adaptation within interpersonal relationships (Wineland & Baker, 2010). In any child, the development of adaptive functioning is greatly influenced by the quality of family relationships (Greenspan, 1997; Sameroff, McDonough, & Rosenblum, 2006). In the presence of intellectual disabilities, the quality of interactions with their own parents is necessary to provide psychological support and adequate stimulation to these children (Pino, 2000).

Several studies on intellectual disabilities have focused on some typical aspects of mother-child interactions, especially on the highly directive attitude often observed in these mothers (Biringen, Fidler, Barrett, & Kubicek, 2005; Neece, Green, & Baker, 2012). Raising a child with intellectual disabilities is a challenge (Hodapp, 2002), both because of the related health problems and because of the difficulty in completely accepting a child who shows more developmental delays compared with his peers. The mother may react by over-caring for the child, with a strong sense of frustration and concern. The mother-child relationship is influenced by these emotional reactions, which can lead to anticipatory, controlling and sometimes intrusive attitudes (Gilmore, Cuskelly, Jobling, & Hayes, 2009;

Terrone & Santona, 2012). In this developmental context, the child with DS is considered as a person less able to send signals, as though he is not the protagonist of his life. He is not helped to resolve his emotional dependency, and he is not granted autonomous expressions of emotional life (Smith, Oliver, & Innocenti, 2001) from which he could develop feelings of self-efficacy and individuation towards an evolutionary path of personal autonomy and social adaptation (Dekker, Koot, van der Ende, & Verhulst, 2002).

The mother-child interaction has been widely investigated, but only recently have researchers turned their attention to the role of fathers in the life of children with disabilities (Olsson & Hwang, 2001; Glidden, Billings, & Jobe, 2006; Shin, Nhan, Crittenden, Hong, Flory, & Ladinsky, 2006). From these studies, it has emerged that fathers of children with DS perceive them as less compromised at the level of adaptation (Ricci & Hodapp, 2003; Hodapp, 2007; Stoneman, 2007; Senese, La Femina, Buro, Saladino, & Di Lucia, 2008). As in typical development, paternal involvement in care is positively associated with the social, cognitive and adaptive development of children (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Cabrera & Tamis-LeMonda, 2002). Therefore, parents of children with DS have to perform many tasks, such as accepting the child in all of his peculiarities, considering him able to grow up, have his own expectations for the future, support his progress and accept possible failures (Pepi & Alesi, 2005; Warren & Brady, 2007).

Parents may believe that their child is not able to become fully aware of himself and, therefore, that he can't live as an adult because he will be always perceived as an infant. This denial of diversity doesn't allow the achievement of the separation-individuation process and consequently a sense of identity. Teenagers with DS begin to feel inadequate compared to their peers, but they do not have the tools to recognize their individuality (Pfanner & Marcheschi, 2005; Wineland & Baker, 2010). Adolescence is, of course, an important and very delicate phase. This is also the period in which individuals with DS explicitly face the issue of autonomy from their parents. The separation-individuation process is an essential condition for the achievement of such autonomy. They feel and perceive the same motivations as their peers, as well as a natural drive towards autonomy. The latter, individuals with DS, limited by their intellectual disability, are full of motivation and desires less likely to be confirmed by the parent; this drive is rarely satisfied through the typical stages, such as new experiences or interactions with the others. Taking into account these considerations, we understand how it is difficult for an adolescent with DS and for his parents

to face the developmental paths of separation and individuation towards personal autonomy. Moreover, the young adult with intellectual disabilities and his parents have to cope with a difficult task: to plan a future for the child which does not involve parental support (Lebri & Montobbio, 2005).

Within the framework offered by the previous studies described above, the exploration of Adaptive Behavior, intended as the set of activities that an individual has to perform daily to be sufficiently autonomous and to adequately perform tasks related to his social role, may be very useful to the early identification of risk conditions which seem to influence relationships among the individual, the family and the social environment.

2. Objectives

The general aim of our study was to analyze the possible interconnections between the development of adaptive behaviors in teenagers with the presence/absence of intellectual disabilities, and their perception of feelings and attitudes within their own family. The main goal was to investigate whether family relationships more oriented towards recognizing the maturational processes of adolescents with DS are positively related to the construction of an adequate self-representation, and developmental paths of personal and social autonomy and adaptive behaviors.

The specific objectives of this research were:

1. To analyze the differences in the levels of Adaptive Behavior and its domains (Communication, Daily Living and Socialization) in adolescents with and without DS, considering the variables of gender and age;
2. To verify any differences in the subscales of the FRTC (De Rosa, 1991) (*Positive and Negative Feelings, Incoming and Outgoing Feelings, Feelings of Dependency, Emotional Involvement*) between the two groups, considering the variables of gender and age;
3. To investigate the relation between the Adaptive Behavior (Communication, Daily Living and Socialization) and Incoming and Outgoing Feelings, Feelings of Dependency and the Emotional Involvement in family relationships.

3. Method

3.1. Participants

The sample consisted of 170 individuals. In the experimental group there were 85 persons with DS and with mild to moderate intellectual disabilities: 36 females and 49 males, aged from 15 to 28 years old ($M = 20.67$ years, $SD = 2.99$). In the control group, there were 85 persons without physical or psychiatric disorders: 37 females and 48 males, whose variables of gender and age were homogeneous ($\chi^2 = 1.26$; $p = n.s.$).

The recruitment of the DS group occurred through preliminary contact with some institutions in central and southern Italy which were willing to collaborate on this research, such as the Italian Association of Down Syndrome in Rome, the Center for Neurorehabilitation "La Spiga", and the ASSORI Association. The non-disabled individuals were recruited in public high schools in central and southern Italy.

The study protocol was reviewed and approved by the Institutional Review Board, and all parents signed informed consent.

3.2. Instruments

During a psychological assessment interview, the following tests were administered: the VABS (Sparrow, Balla, & Cicchetti, 1984; 2003), which assesses the level of Adaptive Behavior through three domains (Communication, Daily Living and Socialization), and the FRTC (De Rosa, 1991), which explores the feelings that the individual expresses and perceives within the family.

The VABS evaluates Adaptive Behavior, which is the ability to perform daily activities required for personal and social self-sufficiency. In particular, it refers to the individual autonomy and independence linked to physical and mental development, self-orientation, personal responsibility, and school and work activities. These skills are expressed in toddlers through activities such as walking, eating, talking and communicating; in school-aged children and adolescents through the ability to adopt social roles at school, in family and with peers; in adults by responsibly participating in family life, administering financial resources and keeping a job (Ferri & Orsini, 2000). Adaptive Behavior is age-related, describes social behaviors and skills, and depends on expectations (Sparrow *et al.*, 1984; 2003).

We elaborated three different versions of the VABS, depending on the number of items and the administration method; the Survey Form is composed of 225 items divided into 3 domains. The Communication domain consists of 67 items and is divided into 3 subdomains: Reception (13 items) mainly refers to the identification of body parts and to the attention towards external information (for example, “He listens carefully to the instructions”); the subdomain of Expression (31 items) refers to the acquisition of communicative skills not only from a syntactic point of view, but also regarding a clear expression of concepts and ideas (for example, “He tells a fairy tale or a TV program”); finally, the subdomain of Writing (23 items) refers to the acquisition of writing and reading skills (“He copies or writes notes or short messages”, “He reads the index of a book”). The Daily Living domain consists of 92 items and is divided into 3 subdomains: Personal Autonomy (39 items) refers to self-care, personal hygiene and health (“He takes care of his personal hygiene without being reminded”); the subdomain of Domestic Autonomy (21 items) mainly focuses on the care and cleanness of the surrounding environment (“He makes the bed when asked to”); the subdomain of Community Autonomy (32 items) refers to practical skills and time and money management (“He chooses his own meal in restaurants”). Finally, the domain of Socialization is composed of 66 items and divided into 3 subdomains: the one of Interpersonal Relationships (28 items) refers to the management of contacts with peers and the recognition of important figures (for example, “He remembers the birthdays of family members and close friends”); the subdomain of Free Time (20 items) focuses on the ability to cultivate interests and to live play and leisure moments (“He has an hobby”); finally, the subdomain of Imitative Skills (18 item) refers to behaviors appropriate to different situations and contexts (“He follows the school or group rules”).

The VABS-Survey Form is administered through a semi-structured interview to a parent or to a person who knows the individual (educators, teachers, etc.).

The FRTC, through the reconstruction of the family circle with the help of cardboard figures and particular items, allows the assessment of the individual’s perception of family relations according to intensity (Positive and Negative Feelings) and direction (Incoming and Outgoing Feelings). It also examines the Feelings of Dependency experienced within the family. The total number of items, finally, is used to state the level of emotional involvement of each person.

The material of the test consists of 20 cardboard figures which are stereotyped and depict vague representations of family members, among

which the individual can choose his own household. There is also another important figure viewed from behind: “Mr. Nobody”, used to collect all the items that don’t belong to any family member. The base of every cardboard figure is a box with an opening on top, in which all the items for each family member are placed. The names of these items are written on coloured plastic cards which are read and inserted in the suitable boxes.

The Adolescents’ Version used in this research (De Rosa, 1991) is composed of 86 items and is used to explore two types of feelings (positive and negative) directed towards the self (incoming) and others (outgoing). In particular, the test explores:

- positive feelings towards others (outgoing) from moderate (for example, “This family member is very nice”) to strong (“I like to be kissed by this family member”);
- negative feelings towards others (outgoing) from moderate (“This family member sometimes has a bad temper”) to strong (“Sometimes I hate this family member”);
- positive feelings towards the self (incoming) from moderate (“This family member likes to help me”) to strong (“This family member likes to hug me”);
- negative feelings towards the self (incoming) from moderate (“This family member sometimes looks at me in a threatening way”) to strong (“This family member makes me unhappy”).
- Moreover, the test explores:
- feelings of dependency relative to maternal hyper-protectiveness (for example, “Mum worries that this person could fall ill”) and to feelings of hyper-indulgence by the parents (“Mum spoils this family member too much”, “Dad overexerts for this family member”).

From the sum of the scores of each individual, it is possible to identify Emotional Involvement (EI), which allows us to know the family member towards which the subject feels more intense emotions (positive, negative, incoming or outgoing feelings), but also if the persons involved are just parents and siblings, or also other family members or “Mr. Nobody”.

Each statement is defined by three parameters: its valency, strength, and direction. The valency of the statement is defined as either “positive” (for example, “I like to cuddle this person in the family”), or negative (“I hate this person in the family”). The strength of the statement is defined as “mild” or “strong”. The direction is either “outgoing” (“I like to hug this person”), or “incoming” (“This person likes to hug me”).

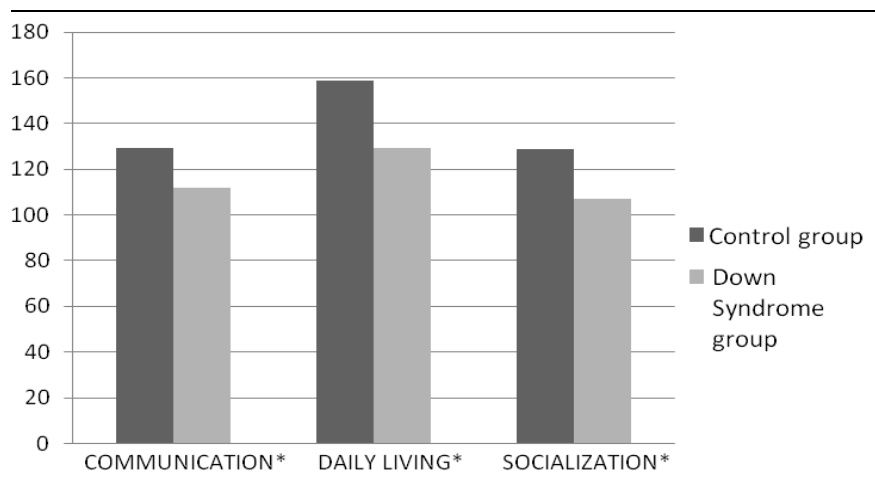
4. Results

4.1. Differences in the levels of Adaptive Behavior - Communication, Daily Living and Socialization - in respect to the variables of group, gender and age.

The data were analyzed using the Univariate Analysis of Variance (ANOVA), considering the VABS domains (Communication, Daily Living, Socialization) as dependent variables, while the variables group (Experimental vs. Control), gender and age (15-19, 20-22, and 23-28 years) were regarded as independent variables. The group was divided into different age categories, as people with Down syndrome show a delay in the development of the psychological dynamics involved in separation and autonomy processes.

The ANOVA on the group factor revealed higher competences in the control group for the three domains of Communication ($F_{(1; 168)} = 149.85; p < .001$), Daily Living ($F_{(1; 168)} = 173.43; p < .001$) and Socialization ($F_{(1; 168)} = 265.56; p < .001$) and for the Adaptive Behavior Composite ($F_{(1; 168)} = 25.27; p < .001$) (Fig. 1).

Figure 1 - Group differences (Control Group vs Down Syndrome) on the VABS domains.

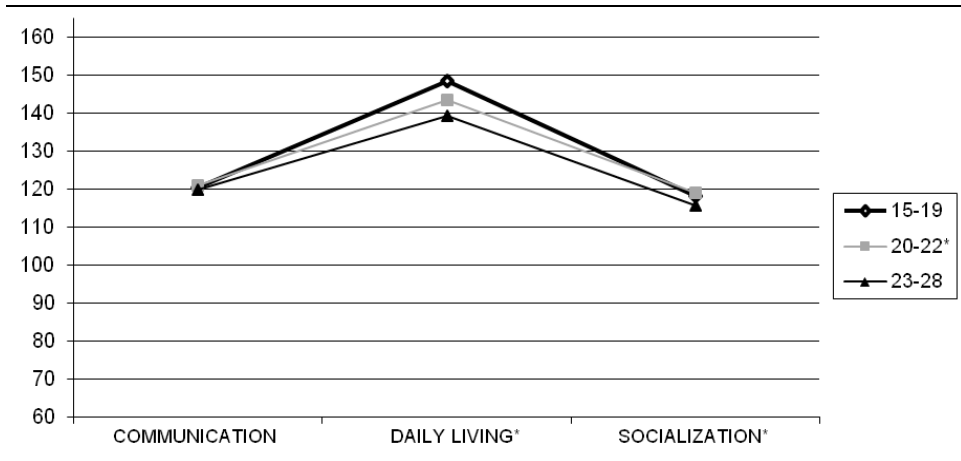


* $p < .05$

The ANOVA for the age factor showed a significant effect on the domains of Daily Living ($F_{(2; 168)} = 7.99; p < .001$) and Socialization

($F_{(2; 168)} = 6.17; p < .01$). The Duncan's tests ($p < .05$) performed on the scales of the three domains showed that, regardless of the group, the scores in the Daily Living and Socialization scales are higher in the age group 20-22 and, over time, tend to decrease (Fig. 2).

Figure 2 - Age differences on the VABS domains.



* $p > .05$

As for the gender factor, the ANOVA showed a significant effect on the Daily Living domain ($F_{(1; 168)} = 8.83; p < .01$), where females ($M = 140.41$) obtained higher mean scores than males ($M = 126.05$).

4.2. Differences in the FRTC subscales - Positive and Negative Feelings, Incoming and Outgoing Feelings, Feelings of Dependency, Emotional Involvement - in respect to the variables of group, gender, and age.

To test the second objective, an ANOVA was conducted on the scores obtained from the adolescents in the FRTC (dependent variable), considering the group, age and gender as independent variables.

The analysis showed that the group factor had a significant effect for the FRTC scales (Positive and Negative Feelings, Incoming and Outgoing Feelings, Feelings of Dependency, Emotional Involvement).

The ANOVA showed that adolescents with Down syndrome obtained higher mean scores in the self-report FRTC related to Incoming and Outgoing Feelings: Incoming Negative Feelings for the Mother ($F_{(1; 160)} = 4.21; p < .05$), Outgoing Negative Feelings for the Self

($F_{(1; 160)} = 34.98$; $p < .001$) and Outgoing Positive Feelings for the Self ($F_{(1; 160)} = 5.77$; $p < .05$). Furthermore, they obtained lower mean scores in Incoming Negative Feelings for “Mr. Nobody” ($F_{(1; 160)} = 21.26$; $p < .001$), Outgoing Negative Feelings for the Father ($F_{(1; 160)} = 5.29$; $p < .05$), Outgoing Negative Feelings for the Brother ($F_{(1; 160)} = 5.36$; $p < .05$), Incoming Positive Feelings for “Mr. Nobody” ($F_{(1; 160)} = 22.22$; $p < .001$), Outgoing Negative Feelings for “Mr. Nobody” ($F_{(1; 160)} = 36.04$; $p < .001$) and Outgoing Positive Feelings for the Brother ($F_{(1; 160)} = 8.25$; $p < .01$) (Tab. 1).

Table 1 - Differences between groups in the self-report FRTC.

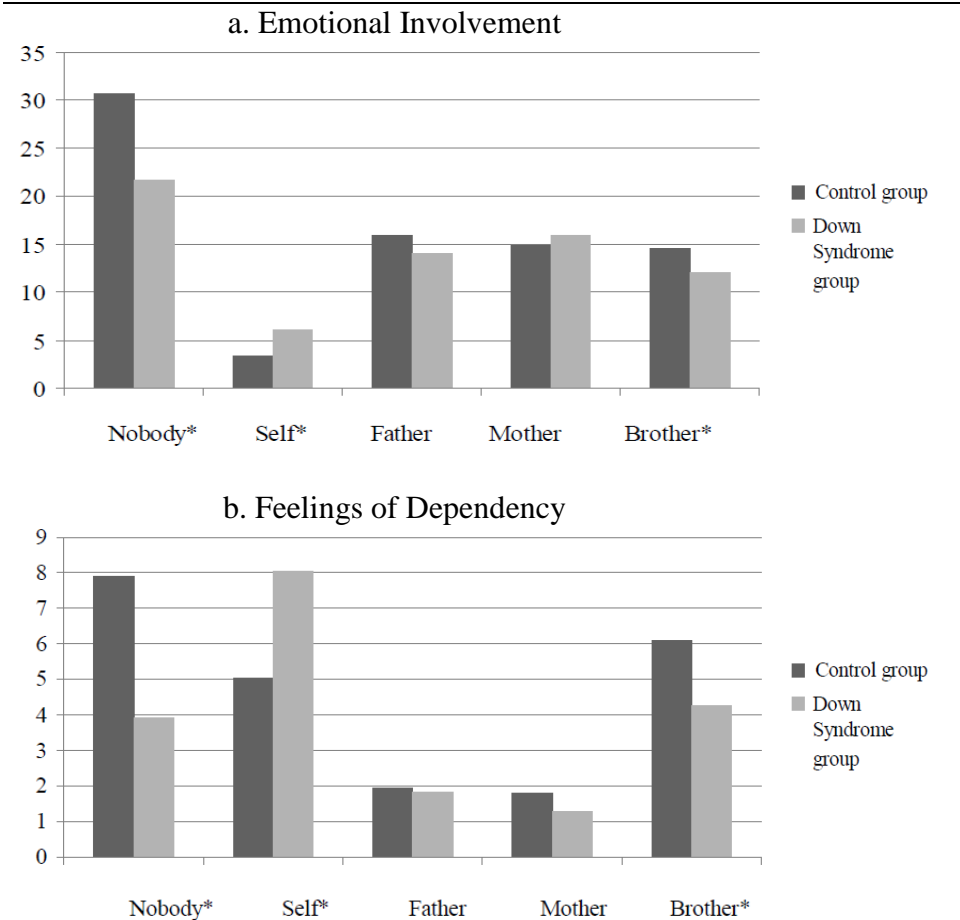
FRTC		Control Group	Down Syndrome Group
		M	M
INCOMING NEGATIVE FEELINGS	Nobody*	10.36	7.68
	Self	.11	.30
	Father	2.89	2.58
	Mother*	2.08	2.76
	Brother	2.17	2.63
INCOMING POSITIVE FEELINGS	Nobody*	6,35	3.90
	Self	.18	.40
	Father	4.68	4.07
	Mother	6.05	5.37
	Brother	3.57	3.19
OUTGOING NEGATIVE FEELINGS	Nobody*	7.39	7.04
	Self*	.79	2.52

* $p < .05$

Moreover, other significant results emerged: Feelings of Dependency for “Mr. Nobody” ($F_{(1; 160)} = 56.62$; $p < .001$), the Self ($F_{(1; 160)} = 30.37$; $p < .001$) and the Brother ($F_{(1; 160)} = 16.88$; $p < .001$), and Emotional Involvement with “Mr. Nobody” ($F_{(1; 160)} = 26.99$; $p < .001$), the Self ($F_{(1; 160)} = 32.68$; $p < .001$) and the Brother ($F_{(1; 160)} = 6.07$; $p < .05$) (Fig. 3, a-b).

With regard to the variables of gender and age, however, statistically significant differences were not found.

Figure 3 (a-b) - Differences between the groups in the self-report FRTC.



* $p > .05$

4.3. Relationship between the FRTC and the VABS scores

An analysis of Pearson’s correlation was done to investigate any significant associations between the Adaptive Behavior measured by the VABS domains - Communication, Daily Living and Socialization - and the FRTC parameters - Positive and Negative Feelings, Incoming and Outgoing Feelings, Feelings of Dependency, Emotional Involvement.

Some significant correlations emerged ($p < .05$), even if the absolute value was statistically low. These results allow us to reflect on the type of relation between the variables investigated (Tab. 2). In this regard, a linear regression analysis was carried out to examine the predictive power of the FRTC factors (Positive and Negative Feelings, Incoming or Outgoing Feelings, Feelings of Dependency, and Emotional Involvement) on each Adaptive Behavior domain (Communication, Daily Living, Socialization and Adaptive Behavior Composite) in individuals with and without Down syndrome. For the measured variables a significant effect was observed ($p < .05$).

Table 2 - Correlations (Pearson coefficients) between the level of autonomy and the perception of feelings according to intensity (Positive and Negative Feelings) and direction (Incoming and Outgoing Feelings), in the groups (Control group vs Down Syndrome group).

FRTC		Control group				Down Syndrome group			
		VABS							
		Communication	Daily Living	Socialization	Adaptive Behavior	Communication	Daily Living	Socialization	Adaptive Behavior
Outgoing Positive Feelings	Nobody	.045	-.005	.03	.022	-.018	.092	.009	.028
	Self	.033	-.136	.062	-.047	-.04	-.155	.054	-.066
	Father	-.222*	-.021	-.209	-.159	.13	.055	.013	.087
	Mother	-.105	-.226*	-.096	-.202	-.247*	-.287**	-.195	-.261*
Outgoing Negative Feelings	Brother	.018	-.228*	-.058	-.154	-.088	-.058	-.073	-.091
	Nobody	.038	-.165	.111	-.043	-.096	-.215*	-.102	-.171
	Self	-.068	.171	-.193	.005	-.172	-.127	-.16	-.172
	Father	.107	-.102	.033	-.017	-.139	.055	.04	.022
Incoming Positive Feelings	Mother	-.01	.296**	-.041	.157	.282**	.105	.108	.164
	Brother	-.101	.123	-.224*	-.045	.024	.131	.083	.094
	Nobody	.065	.219*	.118	.196	-.036	.057	-.058	-.014
	Self	-.001	-.016	-.061	-.034	-.026	.099	.075	.057
Incoming Negative Feelings	Father	-.168	-.274*	-.334**	-.344**	.081	-.01	.031	.055
	Mother	-.137	-.309**	-.193	-.300**	-.218*	-.243*	-.165	-.229*
	Brother	.018	-.367**	-.09	-.249*	-.081	-.149	-.036	-.12
	Nobody	-.033	-.21	-.031	-.147	-.068	-.257*	-.161	-.213*
Feelings of Dependency	Self	.04	.2	.066	.157	.034	.092	.073	.072
	Father	.063	.056	.023	.06	-.054	.064	.032	.067
	Mother	-.029	-.003	-.187	-.085	.153	.101	.124	.14
	Brother	-.048	.109	-.067	.024	-.045	.132	.041	.054
Emotional Involvement	Nobody	-.027	-.246*	-.237*	-.249*	.019	.056	-.055	.009
	Self	.006	-.008	-.021	-.011	.055	-.136	.103	-.022
	Father	-.075	-.335**	-.104	-.262*	-.078	.115	-.114	-.009
	Mother	-.153	-.318**	-.171	-.301**	-.151	-.081	-.145	-.139
	Brother	.054	.131	.034	.106	-.04	.063	.112	.065
	Nobody	.037	-.074	.079	-.002	-.079	-.129	-.116	-.141
	Self	.007	.013	-.034	-.004	-.125	-.114	-.042	-.112
	Father	-.127	-.184	-.253*	-.247*	.037	.055	.041	.089
	Mother	-.157	-.167	-.253*	-.245*	-.052	-.168	-.081	-.114
	Brother	-.066	-.157	-.238*	-.208	-.067	.019	.023	-.016

* $p < .05$; ** $p < .01$; *** $p < .001$

Considering the parameters of the regression analysis, it emerged that, considering non-disabled people, all feelings (Incoming and Outgoing Feelings, Positive and Negative Feelings, Feelings of Dependency) referred to all family members (Father, Mother, Brother/Sister) predicted the scores on VABS scales (Communication, Daily Living, Socialization and Adaptive Behavior Composite). For these variables, the percentage of variance explained by the model varied from a maximum of 14.5% for the Incoming and Outgoing, Negative and Positive Feelings to a minimum of 12.4% for Feelings of Dependency (Tab. 3).

Table 3 - *Values and parameters of the regression analysis for the Control group.*

VABS	Predictors FRTC		Control group			
			Adjusted R ²	Beta	F	Sig.
Communication	Outgoing Positive Feelings	Father	.038	-.222	4.310	.041*
		Mother	.039	-.226	4.453	.038*
	Brother	.041	-.228	4.547	.036*	
Daily Living	Outgoing Negative Feelings	Mother	.077	.296	7.988	.006**
		Nobody	.037	.219	4.183	.044*
	Incoming Positive Feelings	Father	.064	-.274	6.732	.011*
		Mother	.085	-.309	8.753	.004**
		Brother	.124	-.367	12.883	.001***
	Feelings of Dependency	Nobody	.049	-.246	5.353	.023*
		Father	.102	-.335	10.522	.002**
Mother		.090	-.318	9.331	.003**	
Socialization	Outgoing Negative Feelings	Brother	.039	-.224	4.383	.039*
		Father	.101	-.334	10.416	.002**
	Feelings of Dependency	Nobody	.045	-.237	4.939	.029*
		Father	.053	-.253	5.655	.020*
		Mother	.053	-.253	5.656	.020*
Brother	.045	-.238	4.980	.028*		
Adaptive Behavior	Incoming Positive Feelings	Father	.108	-.344	11.157	.001***
		Mother	.079	-.300	8.186	.005**
		Brother	.051	-.249	5.484	.022*
	Feelings of Dependency	Nobody	.051	-.249	5.488	.022*
		Father	.058	-.262	6.133	.015*
		Mother	.079	-.301	8.255	.005**
	Emotional Involvement	Father	.050	-.247	5.389	.023*
Mother		.049	-.245	5.304	.024*	

* $p < .05$; ** $p < .01$; *** $p < .001$

On the contrary, for adolescents and young adults with Down syndrome, the Incoming/Outgoing and Negative/Positive Feelings toward the Mother predicted the scores obtained in the Communication, Daily Living and Adaptive Behavior Composite domains: in this case the higher variance reached 17.2% (Tab. 4).

Table 4 - Values and parameters of the regression analysis for the Down Syndrome group

VABS	FRTC Predictors		Down Syndrome group			
			Adjusted R ²	Beta	F	Sig.
Communication	Outgoing Positive Feelings	Mother	.050	-.247	5.404	.023*
	Outgoing Negative Feelings	Mother	.068	.282	7.176	.009**
	Incoming Positive Feelings	Mother	.036	-.218	4.154	.045*
Daily Living	Outgoing Positive Feelings	Mother	.071	-.287	7.467	.008**
	Outgoing Negative Feelings	Nobody	.035	-.215	4.034	.048*
	Incoming Positive Feelings	Mother	.048	-.243	5.192	.025*
	Incoming Negative Feelings	Nobody	.055	-.257	5.851	.018*
Adaptive Behavior	Outgoing Positive Feelings	Mother	.057	-.261	6.069	.016*
	Incoming Positive Feelings	Mother	.041	-.229	4.613	.035*
	Incoming Negative Feelings	Nobody	.034	-.213	3.963	.050*

* $p < .05$; ** $p < .01$; *** $p < .001$

5. Discussion

The development of adaptive and social skills in adolescents with DS was analyzed and compared with those of non-disabled peers because of thanks to the interest for some studies (Cicchetti & Ganiban, 1990; Ganiban, Barnett, & Cicchetti, 2000; Dekker *et al.*, 2002), and the importance recognized in self-representations. The latter is defined by the perception of feelings and attitudes within the family and by the acquisition of abilities which promote the development of personal and social autonomy, even in the case of intellectual disabilities (Warren & Brady, 2007).

The statistical analyses allowed us to highlight the differences between the group of adolescents with DS, and the control group in the areas which define Adaptive Behavior, and in their connection with feelings and attitudes perceived within the family.

The results of the VABS showed that the level of development of Adaptive Behavior and its domains (Communication, Daily Living, and Socialization) were significantly lower in adolescents with DS than their peers. These data may appear easy to interpret, since it is a comparison

between individuals with intellectual disabilities and non-disabled peers; however, from a careful reading of the mean scores, the data were in line with some studies conducted on children and adolescents with Down syndrome, compared with non-disabled peers or those with other forms of intellectual disability (e.g., autism). These studies showed that the acquisition of social skills in individuals with Down syndrome exceeded the acquisition of cognitive skills. Moreover, improvement in social behavior was directly proportional to chronological age in all areas of the scale (Loveland & Kelley, 1988; Balboni, 2003). However, as the values of Adaptive Behavior based on chronological age were lower than expected and lower than those of their peers, it was assumed that individuals with Down syndrome do acquire social skills in the same way as non-disabled individuals, but at different times (Cicchetti & Beeghly, 1990; Ferri & Orsini, 2000; Pfanner & Marcheschi, 2005).

Furthermore, this study confirmed the findings of other research regarding gender differences in the Daily Living domain, which is the ability to take care of oneself and to carry out domestic and professional activities. Females with DS, indeed, showed better behavioral skills related to personal, domestic and social autonomy (Ferri & Orsini, 2000; Sparrow *et al.*, 1984; 2003).

As for the analysis on the self-representations within the family, there were significant differences between the group of adolescents with DS and the control group. In particular, in Positive Incoming and Outgoing Feelings, attribution to the self was greater in the individuals with Down syndrome, while the perception of being loved by the Brother was greater in the control group. As for Negative Feelings, there were significant differences between Incoming and Outgoing Feelings. First of all, there was a greater denial by the control group, as they didn't perceive the Negative Feelings that family members felt towards them; individuals with DS, instead, perceived more hostile feelings from their Mothers. Secondly, the control group reached higher scores in the expression of Negative Outgoing Feelings (what the individual feels towards family members). The denial of these Negative Feelings was highlighted especially toward the Father and the Brother, while adolescents with DS mainly directed such feelings to themselves.

As for Feelings of Dependency, statistically significant differences were highlighted: the control group tended to deny these feelings more or to direct them to the Brother. Adolescents with DS, instead, perceived themselves as more dependent on their parents. Finally, the control group tended to deny the emotional involvement within the family except for with the Brother,

while the attention of the individuals with DS was directed only towards themselves.

This data confirmed the findings of other studies on the emotional involvement during the late adolescence, when they focus this involvement on their peers and not just their family members. These behaviors may also develop in individuals with DS, if there is good family and social support which promotes the achievement of autonomy both in the family and in other contexts of everyday life (Buckley, Bird, & Sacks, 2002; Dekker *et al.*, 2002; Biringen *et al.*, 2005).

The Regression Analysis showed a different impact of Adaptive Behavior on each family member in the two groups. For individuals with DS, the Mother was the figure that seemed to have a greater influence on the development of autonomy, while in the control group this influence seemed more distributed among all family members.

It was difficult to compare the findings of this study with others, as they rarely focus on this subject. Regardless, international scientific literature is rich in studies on the involvement of parents in the education of a child with disabilities (Olsson & Hwang, 2001; Smith *et al.*, 2001; Pelchat, Lefebvre, & Perreault, 2003).

Prospective studies have shown that the Mother is the figure more involved in caregiving, which can last for a lifetime in the case of disabilities. Crowe, VanLeit and Berghmans (2000), analyzing the time spent and the activities carried out by the parents of individuals with disabilities, underline that mothers spend more time with their children and are more involved in their daily care (cooking, washing, dressing, etc.), while the interactions with the fathers are more playful. The achievement of autonomy in young adults, with and without disabilities, consists in a gradual transition from being taken care of to taking care of themselves and of their own social and working life. Therefore, the parental involvement in caregiving must be gradually reduced (Smith *et al.*, 2001).

The approach to intellectual disabilities and DS has changed in the last thirty years for the use of new definitions, which attribute not only biological but also social features to the disability, and for the importance recognized in the interaction between individual and environment. It is interesting and useful to consider not just the organic aspects of DS, but also and especially the family dynamics that build up around it. Therefore, it is necessary to highlight that presently the intellectual disability is defined as an association of significant limitations both on mind functioning and adaptive behavior, occurring before 18 years of age (American Association on Mental Retardation, 2002).

Adaptation is a very wide concept and includes different domains (conceptual, social and practical), which in turn contain different skills. As of yet, there has been no solid agreement on the features of adaptive skills and the relation between intelligence and the ability to adapt. The latter, therefore, is still an open question, even if its importance is clear in the definition and diagnosis of intellectual disabilities (Schalock, 1999).

The present study didn't fully answer all the variables which influence the development of adaptive behavior in adolescents and young adults with DS, but it provided a useful reflection on the importance of the family and social contexts during adolescence: it is when the separation-individuation process is essential for the development of personality and autonomy of people with DS.

Therefore, prevention and intervention programs supporting parenting and family relationships should consider the self-representation of individuals with DS, and the relations among all family members from the early rehabilitation phases. The results of this research underline the need to support relations more oriented toward autonomy, especially with the Mother: as a matter of fact, she seems to remain the most important figure for the development of autonomy and personal adaptation in individuals with DS. Our results, in line with other recent findings (Warren & Brady, 2007; Gilmore *et al.*, 2009; Laghezza, Mazzeschi, Di Riso, Chessa, & Buratta, 2010), also emphasize the importance of prevention and support programs oriented towards all kinds of family relations and all family members. It is necessary to renegotiate the relational styles and the individual's self-concept in each development stage of a person with DS.

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