Summary

The positive influence of social contacts and social support found its way into social and psychological science during the last decades. Research is only now beginning to address whether supportive relationships with parents, friends, teachers, grandparents, and important others affect the child or adolescent's social and emotional development. Severe health problems threaten the quality and maintenance of relationships with family and friends, at the same time that these relationships play an important role in coping with illness. Disabilities may result in moderate to severe restrictions in the performance of social roles, related to work, leisure, family, and friendships. Unique stressors associated with disabilities such as chronicity, unpredictability and social stigma place substantial constraints on the ability to maintain and restructure relationships. As a consequence blind and visually impaired adolescents may experience problems in relating with the outside world, and this may influence their own development too.

In September 1994 the University of Amsterdam started a study into the personal networks and social support of blind and visually impaired adolescents, age 14 to 24. This study is carried out in cooperation with a Dutch federation of parents of visually handicapped children (FOVIG). The population aimed at in this study includes all Dutch blind and visually impaired adolescents between 14 and 24 years of age, who have no additional impairments such as hearing or cognitive impairments. The period of adolescence was chosen because it involves many changes, especially concerning the psychosocial development. In this phase of life, people want to fit in a group and don't want to be special or different, for example due to their visual impairment.

Purpose of this study into the meaning of personal network members and their social support for adjustment to blindness or visual impairment and well-being of adolescents, is to gather scientific knowledge in order to improve the possibilities for blind and visually impaired children, adolescents and their parents. An additional aim is to make recommendations to (special) schools, rehabilitation centers and organizations for the blind and visually impaired. In this way, we hope to be of any help to improve the rearing and education situation and enhance the development of blind and visually impaired persons.

The three general research questions of this study are (Chapter 1):

a. What are the structural and functional aspects of the personal networks of blind and visually impaired adolescents, compared with those of sighted adolescents?

b. What is the psychosocial development - as measured by psychosocial characteristics, well-being and loneliness - of blind and visually impaired adolescents, compared with that of sighted adolescents?

c. What is the association between on the one hand several aspects of the personal network and on the other hand psychosocial characteristics, well-being and loneliness of blind and visually impaired adolescents, compared with that of sighted adolescents?
Summary

The theoretical framework of this study is based on the socio-ecological model (Van der Ploeg & Scholte, 1990). Central in this model is the mutual influence of factors in the person and the social environment. Three main subsystems are determined within the social environment: the family, the school and the peer group. These subsystems form the social network of an adolescent. Most of the factors in the person, or personality traits, have to do with cognitive-emotional skills. In this study we call them psychosocial characteristics. Examples of these personality traits or psychosocial characteristics are: self-esteem, locus of control and coping skills. The third kind of factor in the model were demographic and macro-social factors, like unemployment, social economical status and biological disabilities. Besides the distinction in factors concerning the person, the social environment and demographic and macrosocial factors, a second distinction in this socio-ecological model is the one between risk factors and protective factors.

Furthermore, aspects of social capital theory related to health issues (Tijhuis, 1994) and ideas concerning adjustment to visual impairment (Dodds et al., 1994) are included in the theoretical framework. In this way the model included pedagogical, psychological and social variables (Chapter 2).

To compare our results of blind and visually impaired adolescents and sighted adolescents, two reference projects were chosen (Chapter 3). These two projects showed a reasonable correspondence with our study of the personal networks and social support of blind and visually impaired adolescents. The first reference project originated from Leiden University and was entitled: "Personal social networks and behavior problems in adolescence" (Buysse, 1997). The second reference project originated from Utrecht University and was entitled: "Rearing in the Netherlands" (Rispens, Hermans & Meeus, 1996). The instruments used in these reference projects were also used in our study. Therefore they were slightly adapted, because of the computer assisted data collection and the visual impairment of our participants.

Personal interviews seemed to be the best method for our study. In social science, a promising method for all kinds of surveys, including personal interviews, was introduced some years ago: computer assisted data collection (CADAC). Using a computer in data collection improves the quality of survey data. The advantages of CADAC are: less or no missing answers, fixed ranges in answer possibilities, the possibility of randomization in questionnaires, and improved concentration of the interviewers on their task. However, a few disadvantages of CADAC have been described, i.e. using the computer might be threatening for participants and interviewers, and the contact between participant and interviewer tends to be less personal and less sensitive.

For our study on sensitive topics like personal networks, social support, and feelings of self-esteem and loneliness, computer assisted personal interviewing (CAPI) seemed to be the most appropriate method (CAPI). When deciding upon the best method, we had to consider the comparison possibilities of our results with those of sighted participants in reference projects. For a valid comparison of our results with those of sighted adolescents on some
specific instruments and to avoid social desirability bias, computer assisted self-interviewing (CASI) was used for those parts of the interview.

Sixteen interviewers, all female students of special education, attended a three-day course of interview-training. After this training they visited the adolescents in their homes, to interview them for approximately ninety minutes. Several materials were developed to support the interview-process, e.g. a guide containing important instructions for the interviewers, paper answer cards developed to support the participants’ memory, a hardboard cover with braille and magnified numbers, enabling the participants to type their answers.

Most instruments were standardized questionnaires with fixed answer categories, 10% of the interview contained open ended questions. Results of evaluation of standard assumptions of normality, homogeneity of variance-covariance matrices, linearity, and multicollinearity of the data, were satisfactory. Multiple regression analyses were used to determine whether factors like sex, age and degree of visual impairment had any effect on dependent variables like network size, network composition and sources for support. To test differences between groups of adolescents we used T-tests and oneway analyses. Correlations were used to study bivariate associations between variables. We also used an advanced statistic method called: Structural Equation Modeling (SEM), analyzing direct and indirect effects of variables.

Through the cooperation of special schools or revalidation centers, more than 950 visually impaired adolescents (the estimated population of blind and visually impaired adolescents in the Netherlands) were approached to participate in this study (Chapter 4). The response was 37%, 354 adolescents were willing to participate in this study. The total percentage of nonwilling and nonresponding potential participants was higher than expected. However, in view of the results of two studies concerning the nonparticipation group, we consider the group of adolescents who did not want to participate and the group participants, as practically equal.

Of the final sample of 316 respondents, 166 were male and 150 were female. Age was categorized into three groups: 14 through 17 years (N=144), 18 through 20 years (N=98) and 21 through 23 years (N=74). The degree of visual impairment was also divided into three categories: blind (N=60), severely visually impaired (N=58) and moderately visually impaired (N=198). The distribution of background characteristics was satisfactory.

The first research question concerned the personal network (Chapter 5). What is the size and composition of the personal networks of blind and visually impaired adolescents? What is the social support, the balance in social support, and the satisfaction with that support of these adolescents? The average network size of blind and visually impaired adolescents is 15 persons. They have a significantly smaller network than sighted adolescents, who have an average network size of twenty persons. The largest sectors in the network of
Summary

visually impaired adolescents are: friends, extended family, and close family. The majority of network members is nonkin, 10% of the network members is also visually impaired, and professionals are a small part of the network (5%).

Blind and visually impaired adolescents perceive quite a lot of support, especially from parents and peers. They perceive more support from formal network members than from siblings and extended family members. With regard to satisfaction, the majority of the blind and visually impaired adolescents seemed satisfied with support.

What is the correlation between the network aspects of blind and visually impaired adolescents? First of all, the significant correlations were only moderately strong. Correlations between the size of the different groups of persons - sectors - in the personal network show many positively correlations. Indicating that listing many persons in one sector is related to listing many persons in other sectors. The social support scores of the two instruments correlate strongly with each other. Furthermore we found significant positive relations between social support and satisfaction with support. The correlation between parental and peers support was positively correlated too, as was peers support and reciprocal relationships in a network. A large network correlates positively with social support, although in computing the support score we have taken the network size into account. Interesting is the relationship between listing many visually impaired friends on the one hand, and more parental support and more reciprocal relationships on the other hand. Participants with a romantic partner experienced more reciprocal relationships with their network members.

What are the differences with respect to the network aspects between several subgroups in the total group of blind and visually impaired adolescents? In summary, differences within the sample impaired adolescents show that the most influencing background characteristics for network aspects are: living situation, work situation, degree of impairment, and kind of impairment. The characteristics age, time of onset, and dependency on persons as regards mobility influence only in some cases. The only small influence of age and sex is somewhat surprising. In sum, a mix of personal characteristics and environment characteristics influences structural and functional network aspects. However, generally spoken their influence is very low.

In what way do blind and visually impaired adolescents differ from sighted adolescents, with respect to these network aspects? Compared with sighted adolescents, blind and visually impaired adolescents list fewer extended family members, neighbors and friends, resulting in a significantly smaller network. The results of the visually impaired group show more similarity with those of adolescents with behavior problems (Buysse, 1997) than with those of sighted adolescents. Compared with sighted adolescents, blind and visually impaired adolescents receive less support from most of their network members, however not from peers. This unexpected result is also reflected in the less negative reciprocity score. Reciprocity in social support for the impaired group is slightly negative, but more reciprocal than that of sighted adolescents.
However, when visually impaired adolescents older than 18 years are removed from the sample, the total reciprocity in support relations does not differ from that of sighted adolescents. The total social support score still does.

To conclude, blind and visually impaired adolescents proved to have a more similar than different personal network, compared with those of adolescents without impairments. The results showed that for structural network aspects we found relatively more differences, than for functional network aspects.

The second research question concerned the psychosocial characteristics, well-being and loneliness (Chapter 6). It seems that the psychosocial development of blind and visually impaired adolescents is reasonably good. Their self-esteem seems high, as does their internal locus of control. Their acceptance of the impairment is not in an alarming phase, nor is the adjusting process. They seem to feel happy in general, and are not often lonely. However, for loneliness and the use of the most appropriate coping strategies, the results are less positive compared with the results for the other characteristics.

In a correlation analysis, the association between self-esteem, locus of control, coping strategies, acceptance of the impairment, adjustment, well-being and loneliness is studied. Strong associations are found between self-esteem, acceptance of the impairment, well-being and loneliness. Adjustment correlates strongly with well-being and loneliness. The degree of internal locus of control correlates with well-being and self-esteem. For coping strategies, only certain kinds of strategy correlate with other aspects. Often using problem-focused strategies correlates weakly with feeling happy, high self-esteem, a high degree of internal locus of control and often using active coping strategies.

Of the total sample (N=316), approximately 14% seem to experience relatively more problems in one or more domains. For loneliness, this percentage seems somewhat higher. Regression analysis reveals that the following background characteristics have a negative association on the psychosocial development and feelings of well-being and loneliness: being female, feeling dependent on others as regards mobility, having acquired the disorder later in life, and having a progressive disorder. Therefore, for the blind and visually impaired adolescents who do experience problems in one or more domains, these problems correlate mainly with vision-related factors and only weakly with socio-demographic and context factors.

The results of our participants were compared with those of sighted Dutch adolescents, using the results of two reference projects (see 3.3.3). Blind and visually impaired adolescents report a higher level of self-esteem than sighted peers, even when controlled for the age differences of the two groups. In general, they experience quite the same feelings of internal locus of control and loneliness. For coping strategies the results are mixed. Blind and visually impaired adolescents more often use problem-focused strategies, which is a good strategy. But they also more often use avoidance as a strategy, which in general is less appropriate. Sighted adolescents seem happier than blind and visually impaired adolescents, but when the age difference is taken into
account, the degree of happiness of the two groups is equal.

To conclude, the sometimes described or discussed problematic psychosocial development of blind and visually impaired adolescents does not apply to the studied group adolescents. Only a small percentage (around 14%) experience relatively more problems in this regard, but in general this is also the case for sighted adolescents. Both groups, visually impaired adolescents and non-impaired adolescents, show more similarities in this regard than differences. The few differences we did found were only small. Our not alarming results regarding the psychosocial characteristics of visually impaired adolescents in general was confirmed by a recent study (Huurre et al., 1998, 1999). Their results showed that the psychosocial developmental outcomes of many adolescents with a visual impairment were similar to their peers without a visual impairment. They also emphasized the need for more support regarding the psychosocial development of visually impaired girls.

With the third research question we try to provide more insight into the associations between network aspects, adjustment, well-being and background characteristics of participants (Chapter 7). The answer to this question is composed of results concerning three confirmatory factor analyses using the AMOS program, correlational results concerning the meaning of network aspects for other variables in our study, and a large set of Structural Equation Modeling (SEM) results.

The confirmatory factor analyses for the structure within the network aspects revealed a two-factor structure. Factors called the structural network quality and the functional network quality underlie respectively the specific structural and functional network aspects. The strongest indicators were: size of the network, total support, support from peers and satisfaction with support.

One factor called adjustment, was found with the confirmatory factor analyses using the psychosocial characteristics. All the paths of the indicators for this factors were significant, self-esteem and acceptance of the impairment were the most important indicators for adjustment. Besides the joint positive association of internal locus of control and acceptance with adjustment, a negative correlation existed between the error terms of locus of control and acceptance. This means that there also was a contradiction in the results of these two variables: a high score on internal locus of control was associated with a low score on acceptance and vice versa.

An acceptable one-factor structure regarding well-being was found for our data of blind and visually impaired adolescents. All the paths of general happiness, happiness regarding school, circle of friends and sport, and loneliness to the factor well-being were significant. Happiness regarding sport was less important and the general feeling of happiness and loneliness were the most important indicators for the factor well-being. Besides the joint positive association of happiness regarding school and circle of friends with well-being, a negative correlation existed between the error terms of happiness on these two domains. This means that there also was a contradiction in the results of these two variables: a high score on happiness regarding school was associated
with a low score on happiness regarding circle of friends and vice versa.

The three separate factor structures were then combined into one explanatory model regarding the direct and indirect relations between all four factors. Before doing so, we described correlational results of the structural and functional network aspects on the one hand and psychosocial characteristics, well-being and loneliness on the other hand. These correlation results showed a few moderate correlations. In general, the functional network aspects had more meaning in this regard than the structural network aspects. Most important network aspects for the psychosocial characteristics and well-being were: satisfaction with the perceived social support, a reciprocal helping relationship, high support from peers, high total social support, having a romantic partner and listing many friends.

We used the Structural Equation Modeling to study the direct and indirect relations between the four factors in an explorative way. The final most appropriate model that we found was not perfect. We had to make some, theoretical conceivable, changes in creating this model. The model approximately fits, therefore the interpretation of the results should be considered with caution.

Four significant positive paths were found. The first path was between structural network quality and functional network quality. The paths from structural network quality to the other factors - adjustment and well-being - were not significant. The factor functional network quality did have a meaning for adjustment and well-being. These two paths were significant and positive. Because support, and especially from peers, and satisfaction with the perceived support were the strongest indicators for the factor functional network quality, these aspects are the most meaningful for adjustment and well-being too. Adjustment also had a significant strong path to well-being. To conclude, the factor functional network quality is meaningful for well-being because of its direct and indirect effect on well-being. The factor structural network quality is less important in the group blind and visually impaired adolescents. The psychosocial characteristics were also important for well-being. Using this explanatory model explains 69% of the variance of well-being.

Background characteristics of the participants had a few significant effects on the four factors. Sex, kind of disorder and dependency regarding mobility had the strongest effects on the factors. Age and living independently only contributed in some cases to a larger amount of explained variance. The SEM results cautiously indicate groups that are more at risk: younger adolescents, adolescents with a progressive visual impairment, females, participants who feel more dependent on persons regarding their mobility, blind participants and participants living independently.

Similarities and differences of our results compared with the results regarding the meaning of network aspects of the two reference projects were formulated. Similar were the only small effects of network aspects on adjustment and well-being, and especially concerning the meaning of the structural network aspects. Corresponding were the results regarding the importance of support for well-being or behavior problems, with the accent on
the importance on support from peers. In our study the parental support even was less meaningful compared with the results of the two reference projects, but this might have been caused by the older age of our participants.

Chapter 8 contains conclusions and recommendations based on the results of our study. It was concluded that the theoretical framework of this study provided suggestions regarding the choice of variables and the associations between the variables. Our explanatory model tested with Structural Equation Modeling was also based on the theoretical framework. It proved to work very well in our study and provided an insight into how to identify successful groups and groups more at risk. Overall we may conclude, that the theoretical model as provided in Chapter 2, was found and improved in our study.

The participants in this study emphasized the need for attention to issues like: how to cope with oneself and with others. This aspect of the development should therefore always be a part of rearing and supporting blind and visually impaired adolescents. Furthermore, the balance between the necessity of support in some aspects and striving after independence is a very important issue in the life situation of the adolescents.

Functional network aspects proved to be important for the adjustment and well-being of blind and visually impaired adolescents. Because some structural network aspects do relate with functional aspects, they should not be ignored too. Perceiving support from peers had positive associations with adjustment and well-being, it seemed that it is even more essential than parental support in adolescence. Paying attention to the quality or content of relationships with peers was formulated as a recommendation.

Of the psychosocial characteristics, self-esteem and acceptance of the impairment seem to be more essential than the other characteristics. These aspects should therefore always be object of rearing or supporting visually impaired adolescents. Feeling independent and feeling happy are associated with each other, as are receiving support and feeling happy. Attention should be paid to this balance between independence and receiving support.