Outlook on relations: Personal networks and psychosocial characteristics of visually impaired adolescents

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Introduction

In this chapter, the domain (3.1) as well as the general and specific research questions of this study (3.2) are presented. In 3.3, the methods and strategies applied in order to answer these research questions are explicated. Special attention is given to computer assisted data collection and the chosen reference projects. These reference projects were used to compare the results of blind and visually impaired adolescents with those of adolescents without disabilities. The composition of the questionnaire is described in 3.4; this is followed by an elaboration of specific procedures as developed for this study (3.5). Finally, in 3.6, the pilot study carried out to test the method and procedures is expounded.

3.1 Domain

The aim was to study the personal networks and psychosocial characteristics of all blind and visually impaired adolescents aged between 14 and 24 living in the Netherlands. In this country, approximately 320,000 people suffer from a visual impairment; this figure represents 2 percent of the population of 16 million (Melief & Gorter, 1995). Of all children up to and including the age of 18, around 0.1% have a visual impairment (Meire & Delleman, 1987;
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Gringhuis, Moonen & Van Woudenberge, 1996). Other researchers estimate this figure to be 0.27% (Melief & Gorter, 1995). No recent figures are available concerning the number of blind and visually impaired adolescents.

The above-mentioned figures should, however, be interpreted with caution, since there are many problems associated with the definition of 'visual impairment'. On top of this, studies into the occurrence of visual impairment have so far been restricted to visual acuity. They have not taken into account other important factors that influence visual functioning, such as reduced peripheral vision, sensitivity to contrast and the influence of light. Furthermore, the occurrence of visual impairment in childhood is so low that it is very difficult to measure.

In principle, we approached our targeted participants, blind and visually impaired adolescents, via rehabilitation centers and special schools for the blind and visually impaired where at some time between 1990 and 1995 they had received services (see 4.2.1). This does not automatically mean that every adolescent is currently receiving support or help from these centers or schools. A small proportion of blind and visually impaired adolescents - namely those who had not contacted a rehabilitation centre or special school in the preceding five years - could not be reached by this method. Therefore, announcements were placed in magazines published by foundations for blind and visually impaired persons. We also contacted associations for blind and visually impaired persons - especially those concerned with adolescents - in order to get in touch with possible participants. Considering all this, the research can be seen as a population-wide study.

3.2 Research questions

Ideas about the positive influence of social contacts and social support in general have in the last decade found their way into social and psychological science. It has now been well established in social science literature that social support enhances physical and psychological well-being and buffers the negative effects of life stress (Cauce, Mason, Gonzales, Hiraga & Liu, 1994; Robinson, 1995). Social support from personal network members can improve coping in adulthood, as well as in childhood and adolescence. However, researchers have only recently begun to address the question whether supportive relationships with parents, friends, teachers, grandparents and other important persons affect the social and emotional development of adolescents (see Chapter 2).

As described in Chapter 2, the social and emotional development of blind and visually impaired adolescents has been a topic of scientific studies. In the Netherlands, however, there has so far been no nationwide scientific study on this topic. Studying the importance of social contacts and social support for the social and emotional development of blind and visually impaired adolescents seems promising, since social support can improve coping with stress. This coping process is also described as 'adjustment', i.e. the process of responding to
life's demands with the added stress of a visual impairment (Tuttle, 1984, 1987). Adjustment is determined by various emotional and cognitive characteristics, including well-being, self-esteem, acceptance of blindness or visual impairment, and locus of control (Dodds, Craig & Flannigan, 1996). These factors are regarded as forming an operational definition of adjustment. The main interest of this study is the meaning of personal network members and the social support provided by these network members, for adjustment to blindness or visual impairment in adolescence. Chapter 2 contains detailed information on these concepts.

As mentioned in Chapter 1, we aim 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.

The three general research questions are:

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?

These general research questions are elaborated into eleven specific research questions, which contain the operationalized aspects and characteristics, based on the theoretical framework as described in Chapter 2. These specific research questions functioned as a guide throughout the analysis of this study.

a.1 What is the size and composition of the personal network 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?

a.2 What is the correlation between the network aspects of blind and visually impaired adolescents?

a.3 What are the differences with respect to the network aspects between several subgroups in the total group of blind and visually impaired adolescents?

The subgroups (see next page) were chosen as a result of the preferred theoretical framework and previous results on this subject (see Chapter 2):
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- blind, severely visually impaired, and moderately visually impaired adolescents
- male and female adolescents
- age groups: 14-17, 18-20, 21-23 years of age
- congenital or acquired visual impairment
- stable or progressive visual impairment
- level of independence as regards mobility
- different housing conditions
- regular education, special education, or both
- different job situations
- different ethnic or cultural backgrounds.

a.4 In what way do blind and visually impaired adolescents differ from sighted adolescents with respect to these network aspects?

b.1 What is the psychosocial development of blind and visually impaired adolescents, based on psychosocial characteristics (i.e. self-esteem, locus of control, coping strategies and acceptance of the impairment), well-being and loneliness?

b.2 What is the correlation between psychosocial characteristics, well-being, and loneliness of blind and visually impaired adolescents?

b.3 What are the differences with respect to the psychosocial characteristics, well-being and loneliness between several subgroups (see question a.2) in the total group of blind and visually impaired adolescents?

b.4 In what way do blind and visually impaired adolescents differ from sighted adolescents with respect to these psychosocial characteristics, well-being and loneliness?

c.1 What is the association between on the one hand aspects of the personal network and on the other hand psychosocial characteristics, well-being and loneliness of blind and visually impaired adolescents (an explanatory model)?

c.2 What are the direct and indirect effects of several background characteristics of participants on the explanatory model of the associations between variables (see question c.1)?

c.3 In what way do blind and visually impaired adolescents differ from sighted adolescents with respect to these associations?

In table 3.1 a summary is presented of the concepts in this study.
Table 3.1 Summary of concepts

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<th>Psychosocial characteristics</th>
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3.3 Method of data collection

In this section our choice between a face-to-face interview and a paper-and-pencil questionnaire is explained (3.3.1); followed by an elaboration of the advantages and disadvantages of computer assisted methods of data collection (3.3.2). Finally, in 3.3.3, two reference projects are described.

3.3.1 Face-to-face interview

Which methods of data collection would be suitable for the purposes of our study? Several arguments played a role in choosing between paper-and-pencil questionnaires and face-to-face interviews. Firstly, in any survey on sensitive, personal topics a personal interview often proves to be a better method for obtaining high data quality, compared with paper-and-pencil surveys (De Leeuw, 1992). Secondly, a disadvantage of self-administered questionnaires is that they are restricted to relatively simple questions (De Leeuw, Hox & Snijkers, 1995). Thirdly, a paper-and-pencil survey in our study, would have required the use of braille and different ways of enlargement, because of the visual impairment of the participants. On the basis of these three arguments, personal interviews seemed to be the best method for our study.

3.3.2 Computer Assisted Data Collection (CADAC)

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 in several ways (De Leeuw, 1995; De Leeuw, Hox, & Snijkers, 1995), mainly because of its technical possibilities. For instance, item non-response is minimized by computer controlled routing and by checking whether an answer has been entered before proceeding to the next question. In general, participants experience a higher degree of privacy and anonymity with this method, which can lead to more self-disclosure and less social desirability bias. A strong and significant effect with regard to less social desirability bias in favor of computer forms was found in a meta-analysis of 39 studies (Weisband & Kiesler, 1996). These authors found significantly higher self-disclosure in the computer condition. Computer assisted data collection methods are accepted by participants and interviewers alike (De Leeuw, Hox, & Snijkers, 1995; Couper & Groves, 1992). Most of them consider a laptop computer to be interesting, easy to use and even amusing (Zandan & Frost, 1989; Witt & Bernstein, 1992). The majority of research participants have no problem at all using a computer and the interviewing program (Beckenbach, 1992, 1995). Because participants tend to underestimate the time spent answering a computer assisted questionnaire (Higgins, Dimnik & Greenwood, 1987), they become less satiated.

To summarize, 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 (De Leeuw, 1995).

There are several subtypes of computer assisted data collection, i.e. CATI (computer assisted telephone interviewing), CAPI (computer assisted personal interviewing), and CASI (computer assisted self interviewing, in which some questions are read and answered by the participants themselves). The last subtype is CASAQ, (computer self administered questionnaire), which is also called disk by mail (DBM) (Van Hattum & Kef, in press).

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. For example, the questions with regard to the personal network would have been very complex for interviewers to administer in a paper version. In our survey, the interview program took over and handled the questionnaire logic and question flow, thus averting interviewer errors. The interviewer had more time to concentrate on the participant when using such a data collection method (De Leeuw, Hox, Snijkers, 1995; De Leeuw, Hox, Kef & Van Hattum, 1997; Van Hattum & Kef, in press).

When deciding upon the best method, we had to consider the comparison possibilities of our results with those of sighted participants in the reference projects. In one reference project of Utrecht University, a paper-and-pencil survey was used with several instruments (see 3.3.3), instead of a personal interview. For a valid comparison of our results with those of sighted
adolescents on these specific instruments, computer assisted self-interviewing (CASI) was therefore a better choice.

After considering all possibilities, advantages and disadvantages, we decided to use CAPI and CASI; it was thus a mixed-mode CAPI-CASI survey. CAPI enabled the complex questionnaires to be handled in a better way, and CASI provided optimal possibilities to compare results with those of the Utrecht project, and avoided any social desirability bias. We used CAPI in 60% of the survey, and CASI in the remaining 40%. Specific adaptations in our survey that were needed to fit the special needs of our participants are described in section 3.5.

3.3.3 Selecting reference projects

A central facet of our study is the comparison of the results of blind and visually impaired adolescents with those of studies with sighted adolescents. Research projects on adolescents at several Dutch universities were examined in order to decide which were suitable as a reference base. Two projects showed a reasonable correspondence with our study of the personal networks, social support and psychosocial characteristics of blind and visually impaired adolescents. The first reference project was from Leiden University and was entitled: "Personal social networks and behavior problems in adolescence". The second reference project was at the Utrecht University and was entitled: "Rearing in the Netherlands". Instruments used in the projects at Leiden and Utrecht university were for reasons of comparison also used in our study. Both projects are described successively.

The longitudinal project "Personal social networks and behavior problems in adolescence" (Buysse, 1997) focused on comparing the meaning of the personal network and social support between adolescents with and without behavior problems (aged 12-16). Three groups of adolescents were interviewed twice:

- adolescents with behavior problems in residential care (N=63)
- adolescents with behavior problems in day treatment (N=29)
- a reference group of adolescents (N=63).

Face-to-face interviews were used in this project to gather information with regard to structural and functional network aspects and several psychosocial characteristics. We did not use the results concerning psychosocial characteristics from their project, because we preferred the instruments for these characteristics as used in the Utrecht project. The network results of the adolescents from the reference group of the Leiden project were used to compare them with the results of the blind and visually impaired adolescents. We also used the results of the adolescents in residential care for the comparison, because we suspected possible significant results. Because of the small sample adolescents in day treatment in the Leiden project, we did not use the results of these group adolescents. The instruments used in the projects and the adaptations we made, are described extensively in 3.4.
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The project "Rearing in the Netherlands" (Rispens, Hermanns & Meeus, 1996) concerned several rearing domains, i.e. environment, family, parents or educators, rearing style, the child/adolescent and especially the development of the child/adolescent. This project focused on the standard rearing situation of 1,267 families with children who do not have (psychosocial or other) problems. The total number of studied families with children aged between 12 and 18 was 506. All the families were visited at home by an interviewer. After a face-to-face survey, the interviewers left a questionnaire behind, which the adolescent filled in himself; it was picked up by the interviewer at a later date. Several psychosocial characteristics of adolescents were operationalized in this study, i.e. self-esteem, locus of control, coping strategies and well-being. For most of these concepts, paper-and-pencil surveys were used. Only the results of the psychosocial development and the social support of the adolescents (aged 12-18, N=506) were used for comparing purposes with our results. We did not use results of, for example, rearing style or family climate, because this information is not relevant for our research questions. A list of concepts and instruments is presented in table 3.1 in 3.4.2.

3.4 Designing the questionnaire

The choice of instruments was mostly guided by the possibilities for comparison of our results. The instruments used in our reference projects (see also section 3.3.3) were slightly adapted for our study, because of the computer assisted data collection and the visual impairment of our participants. In the next three sections, all instruments of our study are extensively described. Examples of items are also included. For an enumeration of all the questions in the interview, see Appendix I.

3.4.1 Instruments from the Leiden study

From the Leiden study we used the:

- Social Network Map,
- Social Network Grid (Tracy & Whittaker, 1990; Buysse, 1997)

Both instruments were adapted to the computer assisted survey methods and the visual impairment of the participants. For instance, the Social Network Map contains a circle drawn on paper with eight sectors of groups of network members, i.e. close family, extended family (e.g. uncle, aunt, niece), friends, classmates/teachers/-colleagues, club mates, neighbors, professionals/therapists, and peers from the care unit. This is also the fixed order of presenting the questions to the participant. For each sector we asked: 'Are there - extended family members - who are important to you? Write the names of these people in this sector of the map'. The circle was transformed into eight separate questions, one for each group of network members. Examples:
Are there - extended family members - who are important to you? Will you tell me the names of those family members?

Significant network members could only be listed in one sector: for instance, a friend from a football club could only be listed in the sector 'friends' or the sector 'club'. Or, a friend who is also a neighbor could only be listed in the sector 'friends' or the sector 'neighbors'. The participants had to decide where to put each network member.

The total network size is computed by counting all the names mentioned. Information about the network composition is obtained in order to study the size of the eight sectors and the characteristics of the network members (e.g. how many network members are blind or visually impaired). See Chapter 5 for detailed information.

The Social Network Grid provides information about the quality of the relationship with network members, especially with regard to practical and emotional support. In the original instrument and in the instrument as used in the Leiden study, paper cards are assorted for each network member or group of network members (e.g. friends). We did not use these paper cards in our study; they would have led to practical problems due to the visual impairment of the participants. Instead of the original materials, the Network Grid questions were asked one by one for each listed network member or group of network members in the personal network of the participant.

The first set of questions concerned the perceived and received practical support, the second set the perceived and received emotional support. Examples:

How often would your father help you with practical problems, like driving you somewhere, helping with an odd job or taking care of your things when you go away?
How often did you actually receive that kind of support from your father?

How often would your friends help you with emotional problems, like comforting you when you feel sad, being there for you when you are feeling down and listening when you want to talk?
How often did you actually receive that kind of support from your friends?

The response categories for perceived support were, on a three point-scale: 1=never or almost never, 2=sometimes, 3=almost always or always. The response categories for received support were, on a six point-scale: 1=never, 2=less than once a month, 3=approximately once a month, 4=approximately twice a month, 5=approximately once a week, 6=a few times every week.

The third set of questions concerned the reciprocity of support for each network member of group of network members: what is the balance between support giving and support receiving for this person? Response categories were: -1=more support receiving than support giving, 0=reciprocal relationship, +1=more support giving than support receiving.
Several questions about satisfaction with regard to network aspects were added by the researcher. The first two concerned satisfaction with regard to practical and emotional support, respectively: how satisfied are you with the practical/emotional support you receive? Response categories, based on a five point-scale, were: 1=not satisfied, 2=not very satisfied, 3=satisfied, 4=very satisfied, and 5=extremely satisfied. The other questions concerned satisfaction with regard to the number of significant others regarding support providing, the number of significant others regarding social activities, and the character of the contact with significant others. These were 'yes' or 'no' questions. Only if a participant was not satisfied, was he asked with which network members he would like to be more in contact with. Several answers to this were possible; for example, a participant is not satisfied with the number of persons with whom he can undertake social activities, and is thinking of more contacts with: visually impaired peers, peers without disabilities, colleagues and neighbors.

3.4.2 Instruments from the Utrecht study

The following instruments from the Utrecht study were used:

- Personal Network List (Meeus & 'T Hart, 1993)
- Cantrill Scale (Cantrill, 1965)
- Rosenberg Self-Esteem Scale (Rosenberg, 1965, 1979)
- Internal-External scale for locus of control (Andriessen, 1972; Andriessen & Van Cadsand, 1983; Rotter, 1966)
- Utrecht Coping List (Schreurs, Willige, Tellegen & Brosschot, 1993).

The Personal Network List (PNL) deals with social support from different sources (father, mother, siblings, romantic relation, best friends, friends, and classmates/colleagues) in three domains, i.e. school/work problems, relational/emotional problems, and leisure time. The first kind of support is regarded as practical support, the second as emotional support and the third as social companionship. Examples:

*If you encounter a problem in school or at work, how good is the support from your best friends?*

*If you encounter a problem in a relationship with another person, how good is the support from your mother?*

*How important is your father in your leisure time?*

The score on the list - a ten point-scale based on tens - ranges from 10 (not important/no support) to 100 (very important/many support). Response '999' is given when someone has, for example, no siblings or best friends. If the father, mother or a sibling had died, or if a romantic relationship had been broken off, the question was asked only if the death/break-up had occurred within the previous year.

The Cantrill Scale and Rosenberg Self-Esteem Scale were used in the Utrecht project as a paper-and-pencil survey. For a valid comparison of the
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results of sighted and visually impaired adolescents, it was necessary to make the surveys as similar as possible. Therefore, we used computer assisted self interviewing (CASI) for those questionnaires (see 3.3.2 for more information on CASI).

The Cantrill Scale measures the sense of general well-being, by asking: how do you feel in general? The response is given on a ten point-scale, by choosing a number between 1=feel really bad and 10=feel really good. Three questions, using the same ten point-scale, were added by the researcher; these concerned the sense of well-being in three domains regarding school, circle of friends, and sport (how do you feel when you think about school/circle of friends/sport?).

The Rosenberg Scale measures self-esteem: how do you feel about yourself in comparison with others? This scale contains ten items with response categories on a four-point scale (1=totally disagree, 2=partly disagree, 3=partly agree, 4=totally agree). A high score on the questionnaire indicates a high, positive self-esteem. Examples:

At times I think I am no good at all.
I feel that I am a person of worth, at least on an equal plane with others.

The IE-scale for locus of control - a Dutch version of Rotter's IE-Locus of control-scale - consists of 18 items with a 6-points response scale (1=totally disagree, 2=disagree, 3=partly disagree, 4=partly agree, 5=agree, 6=totally agree). Factor analysis revealed two factors for the IE-scale: internal control and external control. Examples:

If you really do your best, than you will reach your goal. (internal)
Most of the troubles in life happen to you, and there is not much you can do about it. (external)

The Utrecht Coping List is divided into three groups of coping strategies, i.e. problem-focused strategies (six items), emotion-focused strategies (five items), and strategies focused on avoiding the problem (four items). Problem-focused strategies are mostly used in stress situations in which the subject has a high degree of control; emotion-focused strategies are mostly used in stress situations in which the subject has a low degree of control. Examples:

If I encounter a problem, I immediately try to solve it. (problem-focused)
If I encounter a problem, I feel really somber. (emotion-focused)
If I encounter a problem, I look for some distraction. (avoidance)

The list contains 27 items in total, which are divided into several types of coping strategies; they are not included in Schreurs et al.(1993) three-factor structure, and were not used in the reference projects or our project. Response categories are based on a four-point scale (1=strategy never/seldom used, 2=strategy sometimes used, 3=strategy often used, 4=strategy very often used).
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All these instruments from the Utrecht project were adapted to the CADAC method, so the items and response categories would appear in the right way and one by one, on the screen of the laptop (see 3.4.4).

3.4.3 Other instruments

Some other instruments were applied in order to answer our research questions. With regard to loneliness, a Dutch Loneliness scale for adolescents was used (De Jong-Gierveld, 1984); the scale contains 11 items with a three-point scale: 1=yes, 2=more or less, and 3=no. Examples:

I miss having a really good friend.
I know a lot of people I can trust completely.

For the level of acceptance of the impairment a section of the Nottingham Adjustment Scale (Dodds et al., 1991) was used. The scale contains nine items with response categories, based on a five-point scale: 1=totally agree, 2=agree, 3=neither agree nor disagree, 4=disagree, 5=totally disagree. Examples:

It makes me feel very bad to see all the things sighted people can do which I cannot.
I feel satisfied with my abilities, and my eye problem doesn't bother me too much.

The scales for loneliness and acceptance of the impairment were part of the CASI section of the interview, because of the sensitive and personal character of the questions and comparison possibilities.

To measure the degree or severity of the visual impairment, the Functional Vision Scale (a self-report questionnaire), was adapted from Weiner (1991). The six 'yes' or 'no' items measure functional vision instead of diagnostic information concerning visual acuity. This approach was chosen because of several reasons. Diagnostic information is often indistinct and incomplete, or inaccurate. Besides, it provides little information about the way participants function in daily situations with their visual possibilities. It was almost impossible to obtain data on the visual acuity and other visual information of participants from rehabilitation centers or schools, because many participants had not had any contact with centers, schools or an eye specialist for many years. Even if they were to have had contact, we would have violated their privacy under Dutch privacy laws. An advantage of visual functioning information is its value for understanding the degree of social participation of participants, which gives more relevant information regarding our research questions. Five items from the Functional Vision Scale were used and one item was added. Examples:

Can you see moving objects, like a car driving or people walking by?
Can you see the facial expression on someone's face?
Since an analysis of separate scores on the six items would have yielded too many empty cells or cells with a low number of participants, and therefore would have weakened the power of the test, three categories were formulated based on answers to the six items. If the participants use braille, they were categorized as blind; if they could not read regular print but do not use braille, they were categorized as severely visually impaired; and if they could read regular print, they were categorized as moderately visually impaired.

The questions concerning using one or more devices (e.g. a television magnifier or special glasses), and questions for the level of independence as regards mobility were based on studies by Habekothé and Peters (1993) and Van der Pluijm and Van Dongen (1994).

Alongside the Utrecht Coping List for the general coping strategies of adolescents, a series of twelve questions was used with regard to coping strategies in situations where the impairment is involved. These questions can be divided into the use of passive, active and emotional coping strategies. Four concrete problem situations were described and participants had to state how often they would use a passive, active or emotional strategy in each specific situation (see Appendix I). Response categories were based on a four-point scale: 1=strategy never or seldom used, 2=strategy sometimes used, 3=strategy often used, 4=strategy very often used.

To measure social desirability bias, a scale from Lagerwey (1995) was included and adapted to the computer assisted self-interviewing process. This concept was included as a result of the conclusions and recommendations of several studies into psychosocial aspects of blind and visually impaired adolescents. The scale, which is based on two other instruments (Hermans, 1983; Van der Wolf, 1991) contains eight items with three answer categories: one can be explained as extreme low social desirability bias, the second as a realistic answer and the third as extreme high social desirability bias. Examples:

*I am - very often/sometimes/never* - angry.
*To adults I - never/sometimes/always* - behave politely.

Table 3.2 summarizes concepts, instruments, reference projects and methods.
Table 3.2 Summary of preliminary concepts, instruments, reference projects and methods

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<td>with regard to, for example:</td>
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<td>kind of visual impairment, independency,</td>
<td>Van der Pluijm &amp; Van Dongen (1994) and questions</td>
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<td></td>
<td>CASI</td>
</tr>
<tr>
<td>Social desirability bias</td>
<td>Social desirability scale</td>
<td></td>
<td>CASI</td>
</tr>
</tbody>
</table>
3.4.4 Programming the questionnaire

A computer version of the questionnaire was developed using the software package "Ci3 system" (Hutchinson & Metegrano, 1991). Range checks were defined for almost all questions and several open-ended questions were used. Lists of persons were used in a roster function with the network questions. This roster function programmed the order of specific questions on the list for specific persons. Furthermore, additional interviewer reminders were programmed, e.g. when to hand over the laptop to the participant for the casi part of the interview. The Ci3 system could contain 250 questions at the most. Because our study involved approximately 270 questions, our questionnaire was divided into two parts. The second part was programmed to automatically run after the first one.

The questionnaire was implemented on laptops; a system for making backups and a virus scanner were implemented too. Each laptop was tested before the fieldwork began. A disk-version of the questionnaire was available as a backup, which could be used on the laptop or on a personal computer owned by the blind or visually impaired adolescent if the laptop’s hard disk were to fail. A printed interview guide with general instructions as well as specific ones with regard to the interview program, was available in every interview. Finally, the constructed questionnaire and several procedures were examined in a pilot-study (see 3.6).

3.5 Procedures

Especially in a CADAC-survey, well trained and experienced interviewers are essential. Given these interviewers, the altered interviewing situation is likely to have more advantages than disadvantages, especially when it comes to sensitive questions (De Leeuw, Hox & Snijkers, 1995). Well-trained interviewers are also required to reduce interviewer effects (Van Tilburg, 1998). Sixteen interviewers participated in our study. They were all female university students - from different universities in the Netherlands - with a major in special education and they lived in different provinces in the Netherlands. In this way the travelling time for the interviews was minimalized and interviewers could talk dialect with participants if necessary. The interviewers attended a three-day training program at the University. Topics of the training were how to ask questions without influencing the participant in any way, the contents of the questionnaire, handling the laptop, an introduction to CAPI and CASI, and information about the Ci3 interview program. Very important issues in the training were the special adaptations and special skills that are necessary with regard to our target population, i.e. blind and visually impaired adolescents. In the training video role-playing was used to practice practical and social skills. Part of the training was an excursion to a special school for blind and visually impaired children/adolescents. At the end of the training, the interviewers practiced the interview with members of their own network.
Several materials were developed to support the interview-process, e.g. a guide containing important instructions for the interviewers. Furthermore, several administration forms (e.g. with regard to making appointments with the respondents) were developed.

As mentioned, our interview method was a mixed-mode CAPI-CASI. In CAPI, an interviewer visited the participant and conducted a face-to-face interview using a portable computer. The interviewer asked the questions and typed in the participant’s answers. In the CASI part, the questions were answered and typed in by the participants themselves, instead of by the interviewer for reasons of privacy, sensitivity, social desirability and comparison of our results.

To fit the special needs of blind and visually impaired participants, specific adaptations of the survey were needed. The major adaptation concerned the CASI part of the interview. At the time of the survey, audio CASI equipment was still in an experimental stage, so the following procedure for the CASI part of the survey was devised. Firstly, the interviewer handed the laptop to the participant and moved away from the computer screen. Due to their visual impairment, the participants could not read the screen (well), so the interviewers still needed to read the questions aloud. They read them from a (hard-copy) interview guide. After listening to each question, the participants typed in the answers (which involved pressing just one numerical key) themselves. A device was developed to assist them with typing: a hardboard cover was laid on top of the keyboard, a part of this cover was cut out so that only keys 1 to 10 were accessible; above and under these keys we placed braille and magnified numbers, enabling the participants to type their answers. To synchronize the text of the question on the screen with the words of the interviewer, a series of beeps was programmed with Ci3. These beeps were programmed to sound after the participant had typed a response, so that interviewers knew they could continue with the next question.

Another adaptation was paper answer cards, with the various response categories of the questionnaires. They were developed to support the participants’ memory. We used three versions: one with braille, one with great enlarged letters and one with letters that had been somewhat enlarged.

During the five-months fieldwork period, the interviewers attended lectures at the university in order to receive support for problems that had arisen and to ask questions. The researcher could be consulted by phone, even in the evening and during weekends. Most participants were interviewed at home; some, at their own request, were interviewed at school. No other persons were present during the interviews, thus increasing the feeling of privacy and decreasing a possible social desirability bias.
3.6 Pilot study; testing the method and procedures

3.6.1 Design

To test the interview and the adapted procedures, a pilot study of 18 interviews was conducted. The interviewers were a university student of special education and the researcher herself. Besides testing the general procedures, such as the beeps in the CASI part of the interview, the aim was to determine whether or not adolescents with a visual and cognitive impairment could participate in the main study. Criteria for including these adolescents are:

1. Being able to understand the questions (so the same questionnaire could be used with this group).
2. The length of the interview must not exceed ninety minutes.

The adolescents for the pilot study, including four visually and cognitively impaired adolescents, were recruited throughout the Netherlands by employees of rehabilitation centers and special schools for blind and visually impaired adolescents. The possible participants were selected on the basis of several characteristics (they also are presented in table 3.3 on the next page):

- degree of visual impairment
- sex
- age
- congenital or acquired visual impairment
- having or not having a cognitive impairment
- special or regular education
- living with their parents or in a living group of an institute
- cultural background.

All the participants were interviewed at home. At the end of the interview, both participant and interviewer filled out an evaluation questionnaire.
Table 3.3 Characteristics of participants: pilot study

<table>
<thead>
<tr>
<th>Characteristics of participants (N=18)</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>blind</td>
<td>5</td>
</tr>
<tr>
<td>visually impaired</td>
<td>13</td>
</tr>
<tr>
<td>male</td>
<td>9</td>
</tr>
<tr>
<td>female</td>
<td>9</td>
</tr>
<tr>
<td>14-16 years</td>
<td>5</td>
</tr>
<tr>
<td>17-20 years</td>
<td>11</td>
</tr>
<tr>
<td>21-24 years</td>
<td>2</td>
</tr>
<tr>
<td>congenital impairment</td>
<td>5</td>
</tr>
<tr>
<td>acquired impairment</td>
<td>13</td>
</tr>
<tr>
<td>no cognitive impairment</td>
<td>14</td>
</tr>
<tr>
<td>also cognitive impairment</td>
<td>4</td>
</tr>
<tr>
<td>regular education</td>
<td>9</td>
</tr>
<tr>
<td>special education</td>
<td>9</td>
</tr>
<tr>
<td>living with parents</td>
<td>9</td>
</tr>
<tr>
<td>not living with parents</td>
<td>9</td>
</tr>
<tr>
<td>Dutch cultural background</td>
<td>14</td>
</tr>
<tr>
<td>other cultural background</td>
<td>4</td>
</tr>
</tbody>
</table>

3.6.2 Experiences and adjustments

The experiences of most of the participants were positive. The interview was considered interesting, well constructed and as not having lasted too long. Several critical remarks were made, however, with regard to the fixed response categories of various scales in the questionnaire. The specific adaptations, like paper answer cards and the keyboard-cover device, all worked well. Especially appreciated was the CASI part (see 3.2.1) where - for reasons of privacy and comparison possibilities - the participants typed the answers themselves.

Experiences of the two interviewers were mainly positive as well. The order of questions and scales was evaluated as varied. One scale - the locus of control internal-external scale (IE-scale) - proved to be too difficult for most participants and received many criticisms regarding the questions and vague response categories. In the opinion of the interviewers, visually and cognitively impaired participants experienced too many problems concerning the length and complexity of the interview: concentration and attention levels diminished after approximately 45 minutes (see 3.6.3).
As a result of the experiences of the interviewers and the participants, several changes were made to the questionnaire and the procedures; for example, to question wording or the instructions for interviewers. The important changes are described next.

In consultation with the researcher of the Leiden project, some general modifications to the Social Network Map and Social Network Grid were made. Some participants were hesitant to give the names of their network members; in those cases, the initials of the network members were sufficient. To investigate the diversity in the age of the friends of blind and visually impaired adolescents compared with sighted adolescents, a question concerning the age of friends was added.

As a result of the criticism from participants and interviewers concerning the IE-scale for locus of control, this scale was dropped. However, because locus of control could be a very important factor in the adjustment to blindness or visual impairment, we studied several other instruments for this concept. In order to measure locus of control and still have some possibilities to compare our results with that of sighted adolescents, we chose two instruments.

The first was a scale for internal control of personal efficacy in performance (Peetsma, 1992). The scale is comprised of six items with response categories on a five-point scale: 1=strongly disagree, 2=disagree, 3=partly agree, 4=agree, 5=strongly agree. A high score indicates a high level of internal control. The results from Peetsma (1992) concerning sighted adolescents (11-20 years of age) were used for comparison. Examples:

- If I make any plans, I feel really sure that they will succeed.
- When I really want to do something, I am able to learn everything.

The second scale is the locus of control scale from the Nottingham Adjustment Scale (Dodds et al., 1991). It contains four items and the same five response categories as the scale from Peetsma (1992). A high score indicates high internal control. Our results were compared to those of blind and visually impaired British persons. Examples:

- It’s what I can do to help myself that is really going to make all the difference
- It’s up to me to make sure I make the best of my future in these circumstances

Because of much criticism of participants in the pilot study about the amount of negatively formulated items in the scale for acceptance of the impairment, one positively formulated item was added. A final summary of concepts and instruments, after being adjusted as a result of the pilot study, is presented in table 3.4.
Table 3.4 Summary of definitive concepts, instruments, reference projects and methods

<table>
<thead>
<tr>
<th>Concept</th>
<th>Instrument</th>
<th>Project</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background questions with regard to,</td>
<td>Questions based on:</td>
<td></td>
<td>CAPI</td>
</tr>
<tr>
<td>example: kind of visual impairment,</td>
<td>Habekothé &amp; Peters (1993)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>mobility, use of devices, education</td>
<td>Van der Pluijm &amp; Van Don-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>etc.</td>
<td>gen (1994) and questions developed by the</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>researcher</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of visual impairment</td>
<td>Functional Vision Scale</td>
<td></td>
<td>CAPI</td>
</tr>
<tr>
<td>Size of network</td>
<td>Social Network Map</td>
<td>Leiden</td>
<td>CAPI</td>
</tr>
<tr>
<td>Composition of network</td>
<td>Social Network Map</td>
<td>Leiden</td>
<td>CAPI</td>
</tr>
<tr>
<td>Social support</td>
<td>Social Network Grid</td>
<td>Leiden</td>
<td>CAPI</td>
</tr>
<tr>
<td></td>
<td>Personal Network List</td>
<td>Utrecht</td>
<td>CAPI</td>
</tr>
<tr>
<td>Balance in support</td>
<td>Social Network Grid</td>
<td>Leiden</td>
<td>CAPI</td>
</tr>
<tr>
<td>Satisfaction network aspects</td>
<td>Social Network Grid</td>
<td>Leiden</td>
<td>CAPI</td>
</tr>
<tr>
<td></td>
<td>and questions developed by the researcher</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-esteem</td>
<td>Rosenberg</td>
<td>Utrecht</td>
<td>CASI</td>
</tr>
<tr>
<td>Locus of Control*</td>
<td>Scale from Peetsma</td>
<td></td>
<td>CAPI</td>
</tr>
<tr>
<td></td>
<td>Part of Nottingham Adjustment Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Utrecht Coping List</td>
<td>Utrecht</td>
<td>CAPI</td>
</tr>
<tr>
<td></td>
<td>and questions developed by the researcher</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptance of the impairment</td>
<td>Part of Nottingham Adjustment Scale</td>
<td></td>
<td>CASI</td>
</tr>
<tr>
<td>Well-being</td>
<td>Cantrill Scale</td>
<td>Utrecht</td>
<td>CASI</td>
</tr>
<tr>
<td>Loneliness</td>
<td>Adolescent Loneliness Scale</td>
<td></td>
<td>CASI</td>
</tr>
<tr>
<td>Social desirability bias</td>
<td>Social desirability scale</td>
<td></td>
<td>CASI</td>
</tr>
</tbody>
</table>

* The only change, compared with table 3.2.
3.6.3 Target group

Three aspects had to be considered when determining the definitive target group. Firstly, could adolescents with a visual and cognitive impairment participate in this study? Secondly, could blind and visually impaired adolescents who have another serious impairment or chronic disease participate? Thirdly, could participants with a Turkish or Moroccan cultural background participate?

Criteria for participation of visually and cognitively impaired adolescents are (see section 3.6.1): understanding the formulated questions (so the same questionnaire could be used with this group), and the length of the interview must not exceed ninety minutes. The experiences of the two interviewers who interviewed these visually and cognitively impaired participants are not overall positive. Many questions were too complex and hard to understand for the participants. They needed much more clarification and many more examples compared with the participants with no cognitive impairment. The interviewers believe that the required explanations influenced the answers of the participants. Moreover, the participants’ concentration weakened during the interviews. In general, interviews with the visually and cognitively impaired adolescents took more than ninety minutes. In sum, visually and cognitively impaired adolescents are not able to cooperate with the same instruments and procedures. Additionally, the duration of the interview was too long and many concentration problems occurred. Therefore, blind or visually impaired adolescents who also have a cognitive impairment were not included in this study.¹

Adolescents with other impairments (e.g. a motoric impairment or psychiatric problems) were also excluded from the target group for reasons of heterogeneity. Also excluded were adolescents who had problems understanding the Dutch language or insisted on the presence of another person during the interview.

The Turkish and Moroccan participants in the pilot study did not, in general, have the above-described problems of the cognitively impaired adolescents. The main issue was the level of understanding the Dutch language. Therefore, those Turkish and Moroccan participants who could understand Dutch were included in the main study.

¹ Students in special education at the University of Amsterdam started in 1996 a separate study of the meaning of personal networks and social support for visually and cognitively impaired young adults (Maat, Schotanus & Wildenberg, 1998, see Chapter 8).