

A Social and Psychological Support Program for young adults with visual impairment

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Introduction:

In our organisation, Solidarity in Sight (in dutch: Blindenzorg Licht en Liefde) we focus on adults, aged 18 and over, with visual impairment. To keep our work possible in terms of capacity, we use official medical criteria to narrow down our target group. At this moment this means that we actively support people with a maximum sight of 3 points out of ten in their best eye, or with a vision field of maximum 20 %. Although these criteria function as our guideline, we are aware of the grey zone around it, so we try to look at the possibilities for each individual question. Support in this way can also mean that we refer people to more adequate services. Of course we also provide information and advice for anyone who contacts us with questions concerning visual impairment.

Our active support fully depends on the questions asked by the client and his or her significant others. It can obtain support in all life domains, going from psychosocial support to concrete revalidation and training in working with specific devices concerning the visual impairment, such as mobility and orientation training in how to walk with a white cane and learn different paths. As mentioned, we work with multidisciplinary teams and within several partnerships, for instance with the university hospitals of Leuven, Gent and Antwerp. We also organise case management, especially for the elderly, because they often find themselves in a more vulnerable position and need more adequate support in their desire to stay in their own environment for as long as possible.

Because the idea of inclusion runs like a red wire throughout our entire support program, we also invest a lot in sensibilisation and education towards society. A person with any kind of impairment confronts us with an anxiety for our own vulnerability. The acknowledgement of the vulnerability of

the other actually forms the foundation of every democracy. How we deal with vulnerability and impairment is in fact a measure for the democratic extent of our society¹.

As said, in this workshop we'd like to focus on young adults with visual impairment. We hope it can raise further dialogue on this matter and possibly bring some inspiration in your future work with the visually impaired.

Starting point: a few observations

We started off with the intention of creating a support program particular for young adults, following a few observations in our organisation, that focuses on broad spectrum of support for adults with visual impairment.

- We noticed that a subgroup of people, aged 18 to 30, remained as good as absent amongst our clients.
- A various number of these young people, who in childhood were supported by partner organisations specialised in juvenile visual impairment, disappeared off the radar once they turned eighteen, and reappeared in our service programs during their mid thirties or forties. We could remark that, once they re-enter our services, they find themselves in a situation often escalated on several levels in life, because of ongoing problems directly or indirectly due to their (unattended) visual impairment.

For us, these observations raised a number of opportunities:

- What if we could work out a support program that specifically addresses to these youngsters, that invites them and allows them to grow into adulthood and take full part in society while having the possibility to make their own choices to do so, in spite of their handicap.
- What if we could organise this support in a way that it is making itself less and less important, ultimately unnecessary even?

Further investigation by means of a work group:

These main questions in mind, we started up a work group about a year and a half ago.

The initial idea was to create a platform to discuss, to think about and to try to identify

- what it possibly means for a young person to have a visual handicap and how this can have effects on every domain of his life.

¹ This idea concerning the concept of “good-enough” (see further in our text) in terms of a society that includes all human beings, among who people with an impairment, is also brought in a sharp and beautiful way by Julia Kristeva, a French writer and psychoanalyst, in her essay she addressed to Jacques Chirac in 2003, after he was re-elected: *Lettre au président de la République sur les citoyens en situation de handicap, à l'usage de ceux qui le sont et de ceux qui ne le sont pas*. Paris : Fayard.

- if there really is a need for support among this target group? And if so, to what extent? In which domains? Etc.
- And if so, how come we are not reaching them now? What do we need to take into account in any future support program to be as inviting as possible.

Second and ultimate goal was to come to the installation of a broad program of support offering a variety of services to enable these young adults to grow as self sufficient persons by overcoming the obstacles of visual impairment as much as possible in all domains of life.

Setting up this approach in itself raised a few fundamental questions, for instance:

If we wanted to work towards a program that embraces all important ethical pillars in our field of work, such as **inclusion, participation and empowerment**, we needed to make sure that our method was also submitted to these important criteria:

Or: how could we set up a work group that ticked all those boxes, starting with our group composition. From start it seemed very clear to us that a representative group of these young adults should be present in the work group, so we could set up a program *with* them, rather than *for* them.

Because of reasons of content, but also because of uncertainties about group size, we decided to part the first gathering of our work group in two different sessions, taking place at a different time, but repeating a similar exercise in a slightly adapted version. First session with the professionals as participants, second session with the young adults. At the same time, we were aware of the fact that all following steps needed to take place in joint groups (unless contraindicated).

First steps: Session One: brainstorm with professionals

We wanted to make an inventory about how professional care takers see and perceive young adults with visual impairment and at the same time invite them to reflect on how their thinking about this target group is coloured by their own experiences of adolescence. For in our view it is of utmost importance as care taker to be aware of all working personal mechanisms that may influence the relationship with the young adult. As we stress out further on in our deontology, it is very important to take on an attitude that is not judgemental or normative, but tolerant and transparent. As professionals our role is to help create room for and to motivate the youngster to make his own further choices in life. In our experience, it seems very attractive to make decisions for them, rather than with them or allowing them to do so themselves. This is often the case when a care taker is not aware of his own motives that lie underneath his own choice of working with this target group. This however can interfere in or even obstruct the growth process of the client.

So, we started off our first session with an assignment. We asked all participants to bring an object, related to their young adulthood, based upon which they could tell us something about how they experienced this time of life.

Afterwards, we laid out three questions and initiated a brainstorm session, in which they could write down all associations that came in mind, without over thinking this.

1. Associations with young adulthood
2. Specific associations with young adulthood and visual impairment

3. How do I see/think about young adults with visual impairment from my perspective as a professional care taker?

All information was gathered and put next to the outcomes of our second session with the young adults.

Session two: world café with adolescents from this target group.

As preparation, we asked the group of participating young adults to answer a few similar questions as the ones we asked the professionals in session one, but referring to their own experience in having a visual impairment:

1. Which questions can you identify in young adulthood? Which associations can you make, thinking about your own young adulthood? What is nice? What is difficult?
2. Do you regard your visual impairment as an obstacle? Can you give some examples?
3. What are your expectations concerning a good professional support program? How do you like to be addressed to?

Instead of a brain storm, we organised a world café in small groups which enabled us to start up a dialogue, hoping to find some answers concerning three important questions:

- Are there any questions concerning support in this group of people (or are we creating a problem where there is none?)
- And if so, in which themes/domains can we situate them.
- How can we organise ourselves to make a possible support program as inviting as possible, where might we gone wrong in the past in the way we addressed to these youngsters?

Findings and conclusions:

We found that there is in fact a need for support amongst these young adults, in many levels or concerning multiple life themes.

Put across the inventory of the brainstorm with the professionals, we could remark that these young people wrestle through pretty much the same great themes as any other young adult, but have it harder to do so because of their handicap. Important for us to remember is the fact that these young adults basically go through the same search for an own identity, just as much as their peers without an impairment, but they are more limited in doing so because of the reality of their physical handicap. A support program should be directed to this overall human process, that is in fact a process of emancipation (or the human process of- identification - alienation and separation, cfr

Lacan²), but should at the same time acknowledge the fact that there are physical boundaries to overcome and explore and even create the possibilities for overcoming them.

From their particular stories we could extract that stepping into young adulthood, raised a number of new questions and choices related to their own (aspired) identity. Once turned eighteen, youngsters often see this as an opportunity to emancipate from the world of visual impairment they have identified or had to identify with so far. They long for a chance to try and make it work in society without being viewed as merely handicapped/disabled or as being fully dependent of others, whether this being their parents, partners or other organisational services. They report finding it difficult so far to find space to be able to do this, in their own context, but as well in the services offered by organisations, too often organised in a way that it is making choices for them. They feel a need to break free from the label of visual impairment, of being viewed as one with their handicap rather than as being seen as an individual that happens to have a handicap. This makes that, when reaching mature age, they often do not want to rely on further support and disappear. Some of them succeed, but most of them keep struggling. They find that their ideal is not that easy to obtain in reality, because of the limitations caused by their impairment, but also because the process of emancipation is not something that grows overnight. In all-day reality it soon becomes clear that they also have an active responsibility by making difficult, often life altering choices, defining who they are or want to be as a person. Young adulthood is a period in time where they are confronted with all great aspects of life: starting up a relationship or aspiring this, starting a family of their own or aspiring this, taking responsibility for their own household and life maintenance, engaging in a job career... This also means breaking free to some extent from the often perceived as smothering, but

² Cfr. J. Lacan in *Ecrits* (concept le stade du miroir) and P. Verhaeghe in *Identiteit*. If we want to understand something about identity, we have to look within the moving screen of the outside world, that functions as a mirror for this identity.

Our identity is not some deep hidden, invariant core. On the contrary, it is rather a collection of ideas that the outside world has written on our body. Identity is therefore a construction, that has more to do with “becoming” rather than “being”. It already starts at birth, through the process of ‘mirroring’. We learn what we feel, and who we are, because the other is presenting this to us (cfr early mother child relationship). From our baby-time on we continuously hear what we feel, why we feel it and how we should deal with this, through the messages others (at first our mother) give us (cfr. Arthur Rimbaud: *Je est un autre*). This leads to a definition of who we are, who we should be and who we should not be. The starting point is always our body, around which the other is ‘draping’ these different layers of meaning. But the development is not limited to this, identity is always a field of tension between coinciding with and taking distance of the other, and this from the start. Parallel to this first process of mirroring or identification, there is also a second process that runs through this: an aspiration for autonomy, to break away from the other, for separation. Both are important for the formation of our identity, which is always the temporally result of the interaction between coinciding and taking distance. This positioning towards the others, and more explicitly the other sex and the other as an authority, determine two important layers in our identity, that are closely matched to each other. The other as an authority initially tells me how I should deal with my body and that of the other sex: which “pleasure” is allowed, which is not. This brings us to the debate of norms and values, which means that our convictions in this matter are fully embodied in our identity. Freud: our Ueber-Ich/(superego) next to and across to our Ich, (our ego).

So, a good balance between equality and difference towards the other is very important – on a society level as well as within our own positionings. The current attention for matters as integration and tolerance is in fact not an attention for, but rather shows us an illustration of the problem: every debate on ideology and identity has to take into account a necessary balance between equality and difference (and the aggression and fear that comes with this). A society that wants to make all its members as equal as possible, is doomed to fail, just as much as a society that tries to install as much difference as possible.

at the same time safe and convenient context they grew up in. Aspects of life, all in which they need to make choices and overcome obstacles due to their visual impairment. In the work group, they underlined the need for support throughout this process but at the same time they stressed the importance of having enough room to emancipate and take responsibility for the course they want their own life to go.

In the margin of this, we also encountered these remarks:

- The youngsters that were willing to participate proved to be very well-spoken and opinionated and seemed to already have done some work regarding the dealing with their visual handicap and consequences. We needed to be aware that there was a more vulnerable group of people, that was not immediately represented by them, but needed to be addressed to as well. In following sessions we needed to bring this into consideration.
- We could remark that these young people in many cases discussed in the work group referred to their own personal experiences and growth or further questions, which is, on the one hand, quite evident. These however are very particular, subjective situations, and although this provided us with a lot of insights, we needed to be aware that our program rested upon a more general, theoretical framework. A framework to function as a pair of glasses through which we could encounter all individual and particular situations and questions posed by the variety of individual clients. How could we work out a program that left enough space for this individuality, that raised above all particular questions and stories brought up by the youngsters in the group, without at the same time lose the important information they provided. To maintain this overall objective perspective we needed some sort of binding deontological code, based on the theoretical framework used within our organisation. Although aware that this is a difficult task, we made it object of our next session.

Sessions three and four

Now that we identified a general need for support and we located the main domains that needed specific attention in the program, we needed to work out and formulate an ethical framework. A deontology to guarantee the possibility of a necessary emancipation and personal growth of our clients and binding for all professional care takers that would have a future role in the support program.

To do so, we organised a third session with the professionals. We set up a discussion and tried to write the consensus down in a deontological text. In this, we tried to incorporate all previous info from the two preceding sessions with the professionals and the young adults, concerning expectations and vision in how to work with young adults with visual impairment. In this we tried to refer to our general theoretical framework, mainly being contextual/systemic and psychoanalytical.

Because of the importance of this phase, we needed and provided a fourth session to complete this work, by literally reading the text aloud, line after line, and altering sentences together whenever there was no solid consensus. Finally we came to an agreement in both phrasing and in underlying meaning, and from then on, we engaged to take this text as our further guideline and reference in our work with the young adults.

Throughout our thinking and discussing, we centralised the idea of a “good-enough support”, referring to the concept of the “good-enough mother” of Donald W. Winnicott³. A mother that is “good-enough”, is at first addressing herself optimal to her baby and will then gradually, in compliance with the changes within herself and the growing possibilities of her baby, allow shortages and help to cope with those shortages. A concept as “good-enough” helps to keep away from “sentimentalisation”, for instance: organise support from a feeling of pity or compassion for the client, or idealisation.

Thinking about the organisation of our support program in terms of “good-enough”:

- ➔ How could we, as an organisation, work out a program that allows these youngsters to go through this transition into adulthood without (over)protecting them, but giving them enough possibilities and support in our current society to do so.
 - ➔ When is our support good enough? When is it not too much and not too little. When is it the right support at the right time for the right people? How can we allow enough space to make mistakes, for trial and error, like any other adolescent, but at the same time provide enough support to be able to do so in spite of the visual deficit?
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Formation of the program

Put in place all the pieces of the puzzle, mentioned in earlier sessions, we came up with following structure to organise our support program. We kept in mind that the program should, form wise, be

³ Winnicott was a paediatrician and psychoanalyst, focused on the development of children. As a pupil of Melanie Klein and inspired by Sigmund Freud, Winnicott recognised that the child needs to realize that the mother is neither good nor bad nor the product of illusion, but is a separate and independent entity. Winnicott sees the key role of the “good enough” mother as adaptation to the baby, thus giving it a sense of control, ‘omnipotence’ and the comfort of being connected with the mother. This “holding environment” allows the infant to transition at its own rate to a more autonomous position. He sees the micro interactions between the mother and child as central to the development of the internal world. After the early stage of connection with the mother and illusions of omnipotence comes the stage of “relative dependence”, where they realize their dependence and learn about loss. By moving away from the child in well-time small doses, the mother helps develop a healthy sense of independence. Her failure to adapt to every need of the child helps them to adapt to external realities. The good-enough mother needs to give the child a sense of loosening rather than the shock of being ‘dropped’. This teaches them to predict and hence allows them to retain a sense of control. Rather than sudden transition, this letting go comes in small and digestible steps (in which a Transition Object may play a significant part). The final phase of development, to independence, is “never absolute” as the child is never completely isolated. Throughout our lives we are dependent on others, seeking company and belonging. We soon feel lonely if we are isolated for any length of time. The mother’s role is thus first to create illusion that allows early comfort and then to create disillusion that gradually introduces the child into the social world.

adaptable to particular needs and should encounter all aspects mentioned by the young adults, to make this as inviting as possible.

- Main set up stays the individual process a young adult can initiate, where one on one guidance can be provided.

Additional we want to set up two group possibilities:

- One of them being an ongoing support group, where a number of people, amongst who our young adults with visual impairment, can speak freely about their concerns. This is not theme related. A trained care taker is working throughout the group dynamics and what is set up “on stage” (in what the participants bring up at that moment) to make room for an individual process within each participant. The importance here will be to stress not only the – easily found – similarities or identification with the group, but also and more importantly to create room for the existing individual difference in what is brought (separation). Because it is this balance between identification and separation that makes it possible to create mental and emotional room for the creation of own perspectives and choices, or otherwise: for building an own identity. (cfr. Lacan, Verhaeghe).
- The other being a repetitive workshop of three Saturdays, revolving around a specific theme, as identified in the former sessions. First one to start with, will be around ...
It is our goal to organise this workshop as much as possible in cooperation with existing not handicap related services in society, that can function as a bridge for further engagements.

Important is that any young adult, wanting to engage in any kind of support, can put together his own pathway, either consisting of individual support, of group support or of both. This, to meet any individual need.

Fifth session

In our **last and fifth session** of the work group, we came together with the professionals and the group of young adults and we tried to work out the theme related workshops, revolving around identity. To make this workable, we tried to tie this broad concept of identity down to a few concrete angles, based upon the ideas and expectations of the young adults themselves, for instance: social interaction

We opened this final session with a mind exercise, asking our young adults to imagine they walk through a script, we had written out beforehand, as if they were head actors in a short movie.

The script itself concerns a recognisable situation in familiar social interaction. In the script, they are invited to a surprise birthday party organised for a friend they haven’t encountered for a while. The event takes place in a new lounge bar, in a very busy part of town. Idea is to literally encounter all the obstacles they are confronted with in this recognisable situation, starting from the point where they receive the invitation, up to the point where they are leaving the lounge bar to go back home. Using this method, we try to work as “in vivo” as possible, questioning every choice they encounter

within the situation, which enables us to get very direct, concrete and overall information we can work with in our interactive workshops.

Afterwards, we presented the group a few overall questions, concerning practical organisation.

For instance:

- How and to what extent can we involve them in the organisation of these three days.
- What should be the frequency of these three Saturdays?
- Who can take part? Peers with or without visual impairment, or both? Parents? Partners?
- Where should they be located regarding mobility, regarding surroundings. Which other practical issues should we take into account?
- In which inviting activity can we bring up and work out these themes?
- How can we reach young adults with visual impairment? Which canals should we use to address to them?
- Which inviting name can we give our theme related group?
- What are important, inviting or informative elements to write out a brochure?

All questions that help shape our program in both an inviting and motivating way for young adults with visual impairment in all possible particular situations.

And now? ... to work! Planning and implementation:

Goal is to start the program in the first half of 2015.

Things that need follow up before start:

- The installation of an intervision and/or supervision group for all caretakers involved.
- Further structural education and training of all caretakers involved, for instance in how to maintain group dynamics etc.
- The creation and spread of a brochure for young adults, which is inviting, recognisable and which clearly outlines our ethical vision.
- Organisation of the workshops
- Organisation of the continuous group.

Inspiring bibliography:

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APPENDIX: ethical text

In our work with young adults with visual impairment, we pursue maximum inclusion. This entails that our program should focus on maximum participation in and on current society and create maximum possibilities to do so for each individual taking part.

As care taker, we explicitly try to organise adequate support with or by the young adults in question, instead of for/over them. We start from the particular question they pose. This may lead to perspectives and opportunities in which he can build his own future. At all times we respect the particular own nature of the young adult and his own choices.

Important for us, is the continuous possibility to experiment and learn by trial and error. Throughout our program, we want to create a safe and trustworthy environment to do so. The youngster is allowed to fail, to make mistakes or to, for instance, feel hurt. At the same time, we motivate him to work through this, at his own pace, and to grow from his possibilities. We want him to take responsibility for his life and give him the proper tools to empower himself. We consciously create space to make own choices and to be able to bear the consequences of these choices. The given support aims to stimulate the youngster to take an active position, to take initiative. This opens doors to an enhanced self sufficiency and a better self appreciation. As care takers, we have a facilitating and supporting role to play. Our program is without obligation, but at the same time very inviting to make an investment and engagement in the care for oneself.

These young people do not live in a vacuum. To reach them and to develop their possibilities as much as possible, we also take their context and current society into account. Our goal is to bring these youngster up to a point where they can value themselves and they can find a good balance in “giving and receiving” in their further relationships.

To make this work, we take on enough flexibility in the organisation of the program. We take an open, non-judgemental and tolerant attitude: all questions posed by the young adult, are seen as legitimate, there can be no taboo. We see and respect the youngsters as people who have their own way of thinking and their own morality from which they can build further. Any similarity or difference in our own personal way of thinking as care taker is irrelevant. This however demands a continuous reflection on our own position as care taker through means of inter- and supervision and feedback and ongoing education and training.