

Loneliness in autistic people

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www.autscope.org

by

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Welcome to all of you.

My name is Baukje van Kesteren but you can call me Bonnie, if that is easier for you. As you may have read I have written a book about loneliness in autistic people, titled *A hole where your heart is*.^{*} My presentation is based on that book.

The structure of this presentation is as follows

First I will tell you something about my personal history and the history of the book. Then I will outline the structure of the book. The main part of the presentation consists of the experiences with feelings of loneliness of about twenty autistic people, and some other results from the study I did among these people. I will finish with a few conclusions from the foregoing.

First about my personal history and the history of the book

When I was 50, I discovered that I probably had an autism spectrum disorder. I had had serious psychiatric problems since I was 19, and since then I had been asking for help. I indeed had received various types of psychotherapy, but none of them really helped. Although I experienced some support because of the weekly meetings with my respective therapists, nothing really changed. On the contrary, as I grew older life appeared to become more and more complicated.

As I see it now, the main obstacle in getting adequate help was that autism spectrum disorders were not yet known at the time I sought psychiatric help. So I got another diagnosis. My disorder was called 'hysterical character neurosis'; a character neurosis being what nowadays is called a personality disorder. As you may understand, as I received the wrong diagnosis, the help that was offered was inadequate.

At 50, I watched a tv programme about what was called 'highly functioning autists'. I recognized very much of myself in the guests who told about living with ASD. Especially a statement by one of the male guests struck me as something I could have said of myself. He said: "Most things which other people do by intuition, I have had to work out rationally." That was *me*, all over!

^{*} Baukje van Kesteren (2005). *Een gat waar je hart zit. Eenzaamheid bij mensen met autisme*. Amsterdam, Uitgeverij SWP.

Thanks to a woman whom I met on a Dutch mailing list about autism, I found a psychiatrist who was specialized in ASD, and a good 1,5 years after watching the tv-program I mentioned, I got the diagnosis 'autism spectrum disorder'. The psychiatrist left it an open question whether it was Asperger Syndrome or pdd-nos. (Is that how you pronounce it in English - pdd-nos?) Later, when I needed a doctor's certificate for the renewal of my driver's licence, this psychiatrist specified it as 'a subtle form of Asperger Syndrome'.

When it became clear to me that I had ASD, I started studying the phenomenon 'autism'. This way the causes of many problems I had been confronted with and was still confronted with, became clear to me. I also suspected a relationship between my autism and the feelings of loneliness I had had ever since I was a small child. I was not sure if this relationship existed, but I realized that if it did, there must be more people with ASD who feel lonely much of the time. I decided to do a study on the possible relationship between autism and loneliness. On this study I based my book 'A hole where your heart is'. Doing such a study was possible for me because I had graduated as a psychologist in 1987, and because I had several years of experience in social research.

The structure of the book

As you may have read, up till now the book has been available only in Dutch. Of course I would appreciate finding a publisher who is willing to publish it in English and, of course, any help in achieving this is welcome. For now, however, I'm afraid that you must do with what I tell you about it.

I first will tell you something about the structure of the book, in order to give you an idea of the context of the main part of this presentation. The book has four parts. The first part is an introduction to the rest of the book and consists of 4 chapters.

Chapter 1 is about my personal history - that is, a more extensive account of what I have just told you about myself.

In the second chapter I discuss the characteristics of Autism Spectrum Disorders, with examples from my own life.

Chapter 3 is about the antroposophical view on autism. I don't know if 'antroposophy' is a well-known phenomenon in the UK. Antroposophy is a religious movement on the one hand, but on the other hand it has its own medical science, its own agricultural science (called 'biological dynamic agriculture'), its own education (their schools are called free schools) and orthopedagogics (the science of the upbringing of handicapped children). I have written this chapter because in my opinion the antroposophical view on autism is very fascinating and enriching. It is, however, just an extra; it is not essential for understanding the rest of the book.

Chapter 4 is an introductory chapter about loneliness. Here I explain, among other things, the difference between 'being alone' and 'feeling lonely'. Being alone is a situation; you can be alone in your room, at home, in a street; you can go on holiday on your own; or you can live without a partner. This does not necessarily imply that you feel lonely. On the other hand, you can feel lonely despite the fact that you have company, because you do not feel at ease with the people around you, or because they talk about things that do not interest you or with which you are not sufficiently acquainted to take part in the conversation. The book is mainly about this feeling of loneliness, which I would define as 'an unfulfilled longing for being connected'.

So far about the introductory part of the book.

In the second part, which is the main subject of this presentation, about 20 autistic people tell about their experiences with loneliness, or the absence of it.

In the third part of the book I report several visits I made to institutions for health care, special education and the like, and about a few interviews I had with professional service (*care?*) providers, a philosopher and a chaplain in a psychiatric clinic. During these visits and interviews I learned about the professional help that was offered to autistic people. With the philosopher I philosophized about loneliness in autistic people and the chaplain told me about loneliness in psychiatric patients in general, and about what he could offer them.

In the fourth part of the book I draw conclusions from the preceding parts, and give some recommendations.

The experiences of autistic people

As I said, I now will tell you about the experiences of the autistic people I have interviewed. Actually, I did not really interview them, since all questions were asked and answered by e-mail. As you all know, contact by e-mail is often preferred by autistic people. An additional benefit was that I had plenty of time to ask additional questions or to go more deeply into one or more phenomena that were mentioned by the interviewees.

In the stories these people told about themselves, I discovered a couple of leading threads.

1. As a start, not all autistic people are lonely. Striking is Michael's story. Michael leads a life so isolated, that people in a therapy group used to say to him: 'You must feel lonely, since you live such an isolated life.' Because they said this to him, he *tried* to feel lonely, purposely, but he didn't succeed. He still does not know what loneliness feels like. Another story is the one from a mother about her 7-year old daughter. The daughter does not appear to feel lonely, she seems quite comfortable in her own small world, in which only her parents, her grandmother and animals are admitted. Problems arise when she is confronted with people in the outer world who do not understand her.

Then about the people who told me that they do feel very lonely much of the time. In their stories, the following common issues appeared:

2. They have fewer personal contacts than they would like to have. There are two important reasons for this lack of contacts:
 - a. They lack the necessary social skills.
 - b. They are unable to cope with a large amount of contacts; a large amount of contacts easily becomes too strenuous for them. For example, a married woman told me that she is not able to maintain friendships besides her marriage, not even together with her husband. Being married takes so much effort that she lacks the energy to maintain friendships with others. Other interviewees are not married and do have friends, but no more than 1 or 2. This is partly because they are not good at maintaining superficial contacts. They are looking for depth, and depth is something that you can find only in a small number of relationships.

3. When in company, most interviewees feel more lonely than when they are on their own. Non-autistic people are also familiar with this feeling: when you are an outsider in a certain group, you can feel lonely. However, most people who are not autistic, are able to find groups in which they do feel connected and at ease. For many autistic people this is almost impossible.
I hope it is clear that this holds for company in groups of at least three people. In individual contacts no one can be shut out, so that is a different situation.
4. For many of the interviewees, pleasant and meaningful pursuits are a better remedy against loneliness than human company. The drawback of this remedy, however, is that you cannot be endlessly busy. There always comes a time that you need to stop being busy and relax a while. You may want some company then, but if you have few friends, no company may be available.
5. Company in the background, however, can be very pleasant. Examples are Annelies, a married woman of 48, and Wallace, a married man of 57. Annelies has ASD, and although her husband has no formal diagnosis, she is sure that he has ASD, too. Both have their own room in their house; Annelies spends much time in the living room; her husband spends much of his time in his own corner in the kitchen, where his computer and audio installation are. This makes it possible and pleasant for them to share their house. Wallace tells something similar: he is married, but prefers to do his own things on his own. However, it is important for him to know that his wife is at home while he is busy. This prevents him from feeling lonely.

It may sound strange, but besides marriage, visiting a pub can have a similar function. An example is Hedwig, a woman of 47. During the weekends, she needs to actively fight the threat of feeling lonely. That's why she has a routine which is the same for every weekend. On Saturday morning she visits a kind of café or pub where she sits down at a common table, in the Netherlands we call it a 'reading table'. People can sit there and have a drink (most of them will take coffee in the morning) and read the available newspapers. Although talking to each other is always possible, not much is said. What makes this situation pleasant for Hedwig is that she does not need to socialize, to talk to people. They do greet her by name, and the waiter, knowing how she likes her coffee, brings it with two biscuits - one for her and one for her dog, who accompanies her. This fixed ritual prevents her from feeling lonely at least for the time being. She also has routines for the Saturday afternoons and evenings, and the Sundays.

When I was in my twenties I also used to have a favourite pub. I spent several hours a day in this pub, just drinking tea and mostly without talking much to the regulars. Being there and in their company was enough.

6. The loneliness of autistic people is fundamental in character. In most interviewees it started at a very early age, and it stayed for the rest of their lives. One man, however, tells that at a certain moment he did find friends who accepted him and that thanks to this he doesn't feel lonely anymore. This, however, was only 1 interviewee out of 17.

So far about the experiences of the interviewees with feelings of loneliness. I have also asked a couple of questions about related subjects, about which I will tell you now.

Expectations these people have for the future

When I asked these people about their expectations for the future, most of them appeared to be pretty pessimistic about it. This concerns their personal situation as well as developments in society. As for their own situation: many expect that their loneliness will always be there or will even worsen when they grow older, e.g., when their husband dies. Others are afraid that they will never find a suitable education or job. With regard to developments in society, they feel that society is hardening. There seems to be less solidarity with those who are vulnerable, among whom autistic people. As I see it, people like us tend to have little grip on our lives, we often feel like skating on thin ice. Therefore it is important that the society in which we live, cares about us. The idea of a hardening society is experienced as threatening, at least by many of the interviewees.

Comfort and hope

I also asked people what gives them comfort or hope. Some of them answered that faith offers these to them. Others mentioned listening to music, or spending time in nature. Eating food or sweets, was mentioned as well. Several people mentioned pleasant activities as comforting. A woman of 33 said that there was nothing that could comfort her; although having her boyfriend around was supportive to her, and although this took her mind off her situation, it did not comfort her. One or two people, however, had hopes of finding a job or a partner sometime.

For each other

The last questions I asked were about the things autistic and non-autistic people can do for each other, in order to make living with each other easier.

The answers were as follows.

Almost everyone said that they would like to receive understanding, recognition and acceptance from other people. Because it is difficult for non-autistic people to empathize with autistic people, this will ask a lot of patience from them.

In a practical sense they mentioned adapted work situations (e.g., a quiet environment without background music, or an office that needs not be shared with colleagues), as well as adapted housing accommodation (in which noise reduction is also important), and more possibilities to communicate by e-mail with doctors and professional service (*care?*) providers.

With regard to the things autistic people themselves can offer to non-autistic people in order to make living with them easier, several people mentioned that they tried to adapt to other people as well as they could. This, however, can be awfully strenuous, due to their difficulties in understanding the expectations from others and their lack of flexibility. To Wallace, adapting to his wife and children was so strenuous that he called it 'cutting in his own flesh'.

Almost everyone mentioned their willingness to explain about the disorder. Some of them would only explain about it to a small circle of people they trust, others do it the same way as I do: by writing about the disorder or giving lectures.

Conclusions

This was, in short, the second part of the book I have written. In the third part of the book, professional service (*care?*) providers are interviewed. Therefore I can compare the needs which were expressed by autistic people with the professional help that is offered, and see whether demands and offers match each other.

It appears that autistic people above a certain age, say, 25 to 30, tend, as we say in Dutch, to fall between the quay (*kie:*) and the ship - maybe in English I should say that they 'fall between two stools'.

Nowadays, parents of young autistic children receive much more and much better help than a few decades ago, although I cannot say it is always perfect. For young adults there are more services than 10 or 20 years ago, like forms of 'supported living'. For those who get this kind of support, other forms of support are pretty easily accessible as well. (Of course, I am only speaking about the situation in the Netherlands.)

Older people, however, often have never been properly diagnosed. And even if they have been, if they have more or less been able to cope, they will not easily get the help they need. So there still is a lot to do, within professional care as well as outside, to make life more bearable for autistic people than it is up till now for many of them.

Final conclusion

So far about the results of the study I have conducted. However, you may remember that I started the study in order to find out if there was a relationship between my having ASD and my feelings of loneliness. Learning and thinking about the experiences of the interviewees, I recognized so much of myself, that I have concluded that there certainly is a relationship between both. In other words, my feelings of loneliness are more or less caused by my having ASD. This, however, does not prevent me from looking for solutions and from trying to find new friends, or, for that matter, a partner in life.

This is what I intended to tell you about the study I have done. To illustrate the foregoing, however, I would like to read to you a few fragments of the book which I have translated. If there are any questions, we can have a discussion session this afternoon. So I propose that I read a few fragments of the book now. Is that all right with you?

Fragments from the book

Michel (36), pp. 68-69

In fact I have never felt lonely, although I am alone. Even the time when I used to wander around the city because I was afraid to go to college (too many people, too many social things going on), and spent the evenings alone in my room, I didn't experience as lonely. Strangely enough, for quite a while I have *tried* to feel lonely, because people in a therapy group said that my life *was* very lonely. My life seemed lonely in their eyes, so that was how I should feel.

I still prefer being on my own and I often do things all by myself. People still find this strange. "Are you going on holiday on your own?" "Have you been to a concert on your own?" When I do things on my own, I can do them my way and I need not think about how

I should do things. When I am with other people I always have to think about how things ought to be done.

When I visit friends, most of the time I have to force and drag myself to their house. If I do things with friends, I prefer to do something concrete, a movie, a concert. Probably in order to avoid real contact. And there is a subject to talk about. How will the concert be, how was the movie? From there on, I often succeed in talking a while.

Annelies (48), pp. 75-76

Actually, I feel lonely all the time: at work, when I'm with my partner, etc. My mother used to suffer from this all her life (she had bipolar disorder and maybe also ASD). My father, too, has always had these feelings of loneliness in a large measure. Because of this loneliness I often find life hard, and I am afraid of things. My husband is older than I am, and often when I think that something can happen to him, I can start worrying about it very much. He is my only contact and support. I do not have friends or acquaintances, because I cannot handle and maintain these contacts. We have no children either. If something happened to my husband, I would be alone in the world, and that feeling, that fear, often oppresses me. I wouldn't know how to live on without him. I'd better not think about that.

[...]

I often find it hard to accept this handicap, which it is. In the past I tried very hard to fit in as much as possible, but that completely exhausted me, so I stopped doing that. By now I have accepted that it is not feasible for me to maintain other contacts besides the relationship with my husband, not even together with him. By doing so I would cross my bounds and overburden myself. So I have no other choice than to take this limitation serious.

Max (32), pp. 76-77

I always feel lonely, just not always to the same extent. I am 32, I have ASD (I myself think it is Asperger syndrome), as well as ADD. I have never had a girlfriend in the sense of a relationship - I do have a few ordinary friends. I do long for someone who is always (in any case, often) there for me. I hate to be on my own on my birthday (*birthdays are very important in the Netherlands, almost everyone celebrates their birthday with relatives and friends*), and to go to parties all by myself. The holidays are not as warm as in Christmas movies. I do visit my parents and brother for one day, but that is a bit dull. The longing for a partner is strong, during the holidays.

My friends usually say that it will be all right, because I am so nice and social. But there still is something, a reason why I don't succeed in love. I also do not easily like people. Many girls seem to be looking for a boyfriend as a kind of status symbol and are occupied by external things such as appearances. Maybe I am wrong.

My ordinary friends are settling down now and have less and less time for me. In most cases, when I want to see them I need to make an appointment weeks in advance.

I have had sex with a girl twice. I twice asked an escort to visit me. I hope I do not offend you. If so: sorry, I do not intend to frighten you. After that I have never invited an escort anymore. I did like it but I thought it was quite a substitute and not what I was really looking for, real intimacy. But I was thirty and I had never done 'it', so I really wanted to do it for once and I am glad I have. I will never importune a woman just like that.

Henrik (33), p. 77:

Referring to a tv-spot for the Salvation Army:

In the meantime I am still one of these 1 million Dutchmen who have no friends.

Hedwig (47), pp. 79-80

Loneliness is like a leading thread in my life. I am 47 now, and I have known that feeling since my early childhood. By then, the feeling of loneliness was just a fact. I established it, but did not feel bad because of it. I thought everyone felt like that!

At the age of twelve, I started to understand more about myself, and I understood that I was different. It made me sad and sometimes desperate, and very lonely. I was a shy and fearful girl. I did socialize with other kids in my form, but I was more of a plaything to them.

After finishing school, my loneliness became worse. I combined an education with work. I had a lot of contact with peers. But I felt awkward and couldn't find any connection, and I didn't succeed in starting and maintaining contacts. I was afraid of all these people. Outwardly I kept a stiff upper lip and I did my utmost not to show my despair. That took a lot of energy.

Now the loneliness did not leave me anymore. I preferred to be alone, for among other people I felt more lonely because I couldn't succeed in making contact. I didn't know how to handle it, the only thing I could and did was crying. This I did when I had retired to my room.

Thanks to articles I read, I began to suppose that I had autism, but I couldn't talk about it with anybody. I tried to understand myself and I tried to understand why maintaining contacts took so much effort. I found a boyfriend and we moved in together, but after the first excitement the feeling of loneliness slowly returned. Now I also got depressed and from then on for years my thoughts turned only to death. This was the hardest time of my life. I was very reticent and did not know how to express my thoughts.

During the last fifteen years I have spent much energy to giving loneliness a place in my life. An inward struggle between preferring to be alone and still longing for contact with people. Sometimes I avoided people for months, in order to try to accept my loneliness. I tried to find a way of life in which I could feel at ease without people. This often succeeded for a while. But the painful loneliness and the longing for contact always returned. During the last six months I have had, thanks to my dog (and my AS-diagnosis), more contacts with people and the feeling of loneliness is less continually there. It is a part of my life and although, generally speaking, I now have found a better balance in being lonely or not, it remains a difficult aspect) of my life.

Theo (43), p. 81

Friendships with men always more or less end in enmity. Very annoying, but apparently I do not catch various signals and I start to irritate them so much that they begin to dislike me. So I do not go in for it anymore. The last friend thought that I did not maintain the friendship actively enough, that I did not ring often enough, drop by often enough, etc. I also don't know what is proper or not in a friendship. Even if we share a hobby, I handle it in

a different, apparently odd way. And I must admit that I do not miss this kind of complicated friendships. I have my contacts via e-mail and this goes a lot better. But the feeling of being an outsider regularly comes over me. I am chronically uncertain anyway and then I think negatively about myself. I suppose it comes with the disorder.

After a meeting of members of a mailing list for autistic people, Theo writes:

I have experienced our meeting as very worthwhile. As equals among each other Nobody is surprised when you do not join the conversation for a while. Direct questions can be asked without eyebrows being frowned. Also, no silly word jokes or stupid giggling at certain subjects. All in all, a big relief . Finally, 'normal' people to socialize with. That was my experience.

Wallace (57), p. 84

The weekends used to be a horror to me. I would have preferred to go to school or work. Now I have arranged chores at home: Hoovering, making the beds, small repairs on the house, which my wife puts on a list. I do these chores on my own, working together does not suit me. This set structure of meaningful tasks makes me feel very good - I wish I would have known this before!

Wallace (57), p. 96

My world of thought is my companion. I can always be in contact with the 'cosmic spirit' (a kind of mystic experience), who seldom leaves me alone for a long time. I am a very religious person, be it not in the traditional way. I experience the 'cosmic spirit' (God) daily in my life. I know that I am forever part of God's rich experience, and that my life, however it has run so far, has been meaningful. The hymns I learned at school (e.g., 'Do not walk alone') still support me; even if I never sing them, they automatically sing through me.