

Reflections on integrated home assistance in cases of adult disability

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Abstract

I will deal with an intervention of home assistance for a disabled adult, as a springboard for a reflection on the clinical psychology function required in the field of disability. When handling disability, the interventions are mainly to provide substitute functions: the substitute function responds to the letter of the requests made in the contexts that live with disability, such as the family, but if one looks no further, one does not realize that these requests originate in a demand, which needs to be analyzed, seeking a way out of an isolation that immobilizes the relationships between those that deal with disability, leaving them with no prospects. The integrative function that the psychologist can play is addressed to family relations as a whole, so that they will return to dealing with the experience of disability involving the family. In the reported intervention, the product of the relation proposed is the reactivation of the sense of purpose.

Keywords: disability; family; integrated home assistance; clinical psychology intervention; integrative substitution intervention.

In the school of specialization in psychoanalytical psychotherapy¹, one of the aims we pursued was to develop models of intervention related to what we call the new demands, areas of intervention that are both interesting and not obvious, in which to propose a clinical psychology function. On this point, I would like to talk about Integrated Home Assistance².

Integrated Home Assistance is a system of interventions and health services offered at home, meaning the home of the patient, a community facility, an old-age home, or a permanent residential structure. It was created as an assistance model designed to ensure the provision of health services (medical, nursing and rehabilitation care) and social assistance (personal care, provision of meals, home help), by different professional figures. To carry it out, personalized assistance plans need to be drawn up. The Assessment Units in the local area (made up of professionals like the doctor, nurse and social worker) alerted by various figures (G.P, hospital, family) make an assessment of the degree of the person's self-sufficiency, sickness and social distress. Initially, this form of assistance concerned essentially the non self-sufficient aged population and the disabled, but was later extended to other disabilities such as those with AIDS, Alzheimer, and the terminally ill, with the aim of orienting interventions more towards non hospitalizing forms of assistance. In other words it is a service that has the aim of assistance, is an alternative to hospitalization and responds to problems that are judged to be becoming chronic, in a collusive situation that can be understood from this quotation, related to PSN (Italian National Health Program) 1998-2000, which says that: "Care at home involves a considerable change of perspective: it means passing from the patient moving around the facilities that provide services, to the facilities and professions taking the person and his needs as the centre of gravity".

Since November 2011 a colleague and I have had a professional practice in Frascati. The services we offer are consultations for individuals, families and organizations. We are currently promoting our activity and we would like to start from the services for families. We are therefore exploring their demand.

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2 Home assistance specifically featuring health, given the code ADI in the Aged objective project of 1991-95 and the National Health Plan of 1994-96.

In this area there is a cooperative offering services of Integrated Home Assistance to families experiencing problems related to both physical and psychic disabilities. I decided to contact them to discuss what kind of intervention home assistance is, and to understand the problems for which it is provided. I was very interested in understanding the sense of a request like “come to my home”.

I met the coordinator of this cooperative, who showed great interest in the fact that I had contacted her. In the discussion I understood that the cooperative was facing difficulties with non-payment by the Councils (the only body ordering their services) and with the turnover of staff who left the cooperative because they were not paid (I later understood that there could also be another reason: the difficulty of making sense of their work). Also the families, the clients of the service, were beginning to express dissatisfaction with this turnover: they did not want the staff-member to change.

My request for a meeting and the chance to talk about their difficulties was a resource for the cooperative: symbolically, it was a way of activating new resources, to think about what to do, keeping in mind an important stage of change, which was the need to start integrating public funding with payment by the families. The cooperative is responsible for about 100 families requiring the service for a problem connected to the disability of a family member, nearly always an adult.

The disability handled by the cooperative is hard to define univocally: it can be a non self-sufficient aged person, a mentally retarded adult, children with Down’s syndrome, people suffering from loneliness, psychiatric patients, people needing care after leaving hospital, oncological patients, etc. But I understood from this experience that there are also family-members of the disabled person who ask for help for themselves. It is the state of distress of a family group that gives rise to the request and the disability, if seen on an individual level, conceals the real problem.

These families ask for someone to go to their home, stating at the outset that the distress they are experiencing is something that lies within their system of relations, which they manage inside the family. The staff-member who goes to their home represents an element of discontinuity in the fantasy that if you are in distress, it is a private fact that generates constraints, the obligation of assistance, experiences of ambivalence and above all isolation. Not being self-sufficient concerns the whole family, which becomes an isolated system. Isolation is not the lack of relations, but the presence of ritualized relations of control that are always the same. This fact of living as isolates is the first thing the families I met conveyed, and I think it is the experience underlying the request for the service of home assistance.

The cooperative “sends” a staff-member to someone’s home with no other information apart from an address and a very sketchy diagnosis; this staff member nearly always takes on a function of total substitution³ in relation to the request, which means he/she goes to shower the person, take him for a walk, clean the house, in an unchanging repetition. Adopting a function as substitute in relation to the request responds to the letter of the various requests, with no symbolic interpretation of the demand and without dealing with the relation with the family and the disabled person, so the “substitution” comes about by reproducing the collusive acting out that is typical of the family.

One interesting aspect of this kind of service is the way it is provided: whether it is daily or weekly, the feeling is that time is cancelled out. Many families have been using this service for years and the cooperative does not plan the intervention, since the responses are of substitution and seem to be confined to doing what the families ask, with no verification unless through any complaints from the families.

I suggested to the cooperative that the lack of verification of the service offered makes the intervention meaningless, the awareness of who the families are is lost, as well as the relation with them, and they are not known in the living present.

³ For a definition of substitute function see the article *Psicologia clinica e disabilità. La competenza a integrare differenze* [Clinical psychology and disability. The competence of integrating differences], Panaccia, 2012, *Rivista di Psicologia Clinica*, 1, 91-110.

When I asked the coordinator what problems they had with their clients, she told me to go and meet them; it seemed complicated for her to reconstruct the stories unless it was the description of the individual's disability, with no anchorage in the context or in the present. The coordinator and I constructed a two-sided collaboration: on the one hand, to continue the reflection on seeing the whole family as "the client" of their service, and on the other, to work with some families to organize the reassessment of the project of home assistance.

The integrative function as an intervention reactivating resources and sense of purpose

I will report on a case that the cooperative gave me with the aim of reassessing the project of Integrated Home Assistance. That is the explicit reason the coordinator gave when entrusting me with Giacomo and his family; my hypothesis is that the problem this family poses severely challenges the cooperative's fantasy of being able to provide a service without a process of verification; the reassessment seems to indicate the cooperative's need to understand the meaning of this intervention.

Giacomo is a 45-year-old man living with his aged father and his father's wife. His mother died few years ago. He is an only child, whose problems began to emerge at school when he showed learning difficulties. At the age of 14, due to these deficits and to the appearance of strange behavior which at first his father and the doctors put down to adolescence. There began what Giacomo's father describes as a pilgrimage in search of someone that could give a name to his problem. The pilgrimage was the non resignation, the need to understand and to act out the anguish of dealing with something that was not normal. Giacomo had his genome mapped, which revealed a chromosome transmigration.

Giacomo's current diagnosis is serious mental retardation with co-occurring psychosis. The request for home assistance was made by his father and the plan resulted in a home intervention designed to assist Giacomo with his personal hygiene and support him in reading, writing and arithmetic.

I meet Giacomo and his family 3 times a week. Each meeting lasts an hour and a half.

Giacomo and his family have been using this service for about 5 years, and during this time the cooperative has never met them, but knows them from the stories that the various staff members assisting Giacomo report in cooperative meetings.

I start working with this family at the end of March; before my arrival Giacomo was assisted by another staff member who did exactly the same things every time: help him to shower and get him to do writing exercises that were called homework. I first met Giacomo and his family accompanied by this staff member. The cooperative suggests that I meet the family with the other staff member, in the fantasy that by watching one can learn what to do, but symbolically I think the need was to control the variability that the new relationship would generate, a variability feared by the cooperative but also by the family. On my arrival the family entirely delegated to the staff member the task of introducing me, as if there were no problem, whoever comes, one or another for us it's the same, as long as someone comes.

Giacomo's father is a musician, as I said very old and very busy with his artistic work. He has not been remarried long. Giacomo plays the drums well, and his father says he was a child prodigy. The first effect of my presence in their house is that it becomes the time when the father and his wife have a break from relating to Giacomo. When I arrive they leave and Giacomo and I are left alone. All they expected from me was that I would be their substitute in being with Giacomo.

I dealt with these disappearances by thinking of where the family's lack of self sufficiency lay. What were they asking when they wanted someone to go to their house. I hypothesize that this family is not self-sufficient in forming relations. They seem to be in difficulty in constructing relations that have variability, relations that are a potential resource for daily living. In this family all the gestures and all the exchanges seem to be always the same in a frozen time-frame. I am asked to be always extremely punctual, to arrive without the slightest variation, to conform to

the well-known model of relating, to do what the other staff member had done. At the same time however I sense in the relationship with them a marked ambivalence about this isolation. I base myself on their request for someone to go to them.

Giacomo waits for me in the breakfast room, sitting on the sofa in the dark, and he nearly always greets me by telling me what he wants to buy. Each day he wants to buy a new game, a doll, Big Jim, a lorry, and if that is his wish, he compulsively asks: "Do I buy Big Jim? Do I buy Big Jim or not?". Big Jim is a very popular toy which was sold until the mid Eighties, when Giacomo was a teenager. It represented an athletic, sporty young man; for Giacomo Big Jim seems to represent a wish, a part of himself, the image of what he might have been. Giacomo is asking for confirmation. His father is the one who makes it possible for his wishes to come true and his father always answers yes. Giacomo is happy but not reassured, I think he has now understood that his father humors his requests but in the end will only disappoint him.

Giacomo wonders if he will buy, if he will have, and therefore if he will exist or not. I think this is the crux of the family's problem; it is as if at every turn Giacomo insists on asking his interlocutor for confirmation that he exists now, and even more on whether or not he will exist after the death of his father. Giacomo has no other reference points. In his family the problem of organizing Giacomo's future is totally ignored, and never spoken about. On this point, it seems to me emblematic to underline one aspect. Previously Giacomo lived in a residential community, then from the age of 18 to about 33 he lived in his own apartment (bought for him by his father) with an assistant/carer with whom he had established a good relationship. After his mother's death Giacomo came back to live with his father; my hypothesis is that his father could not bear the loneliness and wanted Giacomo to keep him company. The life of the family seems to be seen as a split between before and after the mother's death. In the period before, the family organized other systems of relating for itself and for Giacomo, while the period after is marked by isolation, closure and turning in on itself.

To create a relationship with them, for a while I decide that the meaning they attach to the shower and the homework should be respected; I try however to introduce variations, such as asking how they are when I arrive at the house.

The wife greets me when I arrive, and hearing me ask how things are going takes the chance to tell me all that she does for her husband and for Giacomo, but also to express the difficulty she feels at not being the centre of her husband's interest. The centre is Giacomo, everything is always done for him.

One of the first times I go to their house she asks me if I am from the town. I answer no and ask why she wants to know. She says that this town is full of loose women, prostitutes, very young women who try to seduce her husband and to take Giacomo in by offering to give him toys, in order to get to her husband. She thinks that it is these women who put into Giacomo's head the desire to buy things, who lead him astray, and he then spends the whole time saying what he wants to buy. She tells me that the night before, outside the gate to the house, there was a "dark girl" that she had had to send away rudely. She says: I'm telling you this because you are different (I am a young brunette). I respond that she seems to feel threatened and that she seems to be taking on a great responsibility for her family. The woman looks at me hard, she seems to be trying to control her emotions.

On one of my early visits to their home, on the stairs I meet the father, who says he wants me to take care to make Giacomo write with his right hand (Giacomo cannot bend his right thumb and so cannot hold a pen, but is able to write with his left hand) and says that in the breakfast room there is the elastic band to place between Giacomo's fingers so that he can write properly. This elastic band was thought up by the father. The right hand seems to represent the proper way, normality, the thing to be pursued at all costs, even by tying up his fingers. When I respond that Giacomo can write with his left hand, he answers that since he has been right-handed all his life why should he start writing with his left hand now? Right and left seem to reflect the conflict: he used to be normal, why is he not now? I ask him if he thinks his son might be ambidextrous, and he says he does not know but asks me to check. I see this request as a possibility of talking more about it later.

But what do the shower and the homework represent? I think they are like the elastic band, a support for normality. A ritual that if endlessly repeated might make Giacomo return to what he once was, a gifted child.

Giacomo and I have agreed that he can shower by himself. Before he gets into the tub I help him to get organized. I think Giacomo has no perception of his body, of the front and back; though he can name the parts of the body, he does not associate them. For instance if I say: "Wash your neck now", he says: "Where ?" or else he washes his arm.

Lately Giacomo has asked me: "Is it true that I can't touch my trousers?". I ask him who told him so and he responds: "Nobody...me" and adds: "Is it true that I can't touch my willy?". While he asks these questions, Giacomo once tries to bite me on the shoulder. I talk about it with the wife, who was present when the attempted bite took place; she tells me not to worry, it is a sign of affection.

I talk about it with Giacomo and to do so, start from myself: I tell him he frightened me badly and ask if he meant to bite me. He says "No harm". He looks mortified, frightened, but for the first time does not obsessively repeat something. He seems to be encountering the experience of talking to someone who is speaking to him out of interest in him. His answer makes me think of a small child learning to talk. The same day as the bite the wife tells me she is planning a party to celebrate the release of her husband's latest CD, and is inviting a lot of important musicians, journalists, showbiz people; she also invites me. I start to think that my presence in this family is organizing their sense of purpose, making it relevant, it is giving them a new lease of life, and I wonder how to support this and in which direction.

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