



Social Welfare Corporation Soyokaze no Ie (breeze house)

Activity home in the Konan Chuo area

Excerpt from the public relations magazine “Soyokaze no Ie”

## “To live in the community”

Sachiko Atsusaka

“To live in the community”—how many of ordinary citizens have thought about that?

It is not necessary for them to emphasize about “living in the community”, as the community is just an ordinary part of life, while the idea is very commonly mentioned in the world of children with disabilities.

However, unordinary lives in institutions, which have played a historically important role for persons with disabilities, still exist.

I have been living with Junko, who has a disability, in the community for as long as 19 years.

Soon after the disability was announced in the 18-month checkup, my husband’s parents kicked me out of the house demanding a divorce. Devastated, I didn’t know how I could raise the child.

Holding Junko who was still weak at the age of 2 and clinging to me in my hands, and carrying her baby brother, Ryutaro, on my back, I couldn’t even put up an umbrella because of all the baggage of diapers and changes. Walking wet all over, another woman in me asked me what I was living for.

Just when I was trying to find something to live for as she was slowly starting to grow, the doctor announced to me, “I suspect Rett Syndrome in which the brain gradually ceases to send orders. It’s progressive, so no growth can be expected. There is no specific remedy. Nerves are going to be damaged, so rehabilitation wouldn’t work.” At the dreadful news that she’s going to go backward instead of forward, I didn’t know what to do.

As I wanted her to spend her time with normal children and see her smile, I took her to kindergartens and nursery schools in the neighborhood. The only answer I could get was “no”. They said to me, “What are you doing here?!” , “The trouble would be less worse only if she could take care of herself a little more.”, and “Aren’t there institutions for such children?”

When she entered the elementary school in the community, hoping to make friends, the class teacher said, “Who will wipe the slobber? I am a teacher. The job of teaching doesn’t include wiping slobber.” Tears streamed down my face on the way home on that day. I told myself, “It’s not Junko’s fault, or mine either. It’s just the simple fact that Junko has a disability.”

I have never felt like quitting child rearing, but all those events that made me tired to live are

still vivid in my memory, although it was a long time ago that they happened.

I am not weak anymore and I'm living a good life now. Junko is also gradually growing up, instead of worsening. She even enjoys commuting to an institution. We are absolutely "living in the community".

As a special counselor of "Soyokaze no Ie", I am currently providing counseling services to persons with disabilities and their families, and supporting persons with intellectual disability to live independently. Also, in the organization called Yokohama Welfare Network, I am doing ombudsperson (also known as ombudsman) activities to protect rights mainly of children with disabilities who are in residential institutions.

When I meet mothers who are feeling the way I used to, I want to help them to live positively and bravely as much as possible.



**●In order to "live in the community", both parents and children have to stay healthy!!**

While counseling residential persons as an ombudsperson, they say "I want to go home." or "I want to see my mother." It implies that they were forced to become residential against their wills because of critical situations such as sickness of the supporting family members, which reveals the insufficiency of the community supporting system to allow families to live together.

There are also some cases of child abuse, in which they say, "When my father was hitting me, my mother just looked on without doing anything.", "I want to kill my parents.", and "I want to die." I have learned how difficult it is to support children who don't know how to be positive about themselves or respect others because of the fact that they have never been loved by their parents and therefore can't trust them.

A residential institution is a special space where all the doors are locked. Not to mention going out, they are not allowed even to move around within the building, which eliminates the opportunities to mingle with other people even for those who are totally capable of making conversation. As everything from space with the staff to the life in general including clothing and eating is under control of the institution, the meaning of "living in the community" has a huge gravity.

I can't help but wish that they will expand human relations with people in the community in addition to those with devoted supporters of institutions, learn how to "live in the community" through help of citizens and the community, and at least enjoy their lives.



- **There are more different things than just health that are necessary in order to “live in the community”, because it means living in the common society in stead of a special space ! !**

The counseling services of “Soyokaze no Ie” deal with all kinds of problems, none of which are the same as one another. It is necessary to understand needs of each individual and his/her family and plan how to support.

There are some persons with disabilities who dared to take up employment but are bullied into suicide attempt or social withdrawal.

Some were enjoying work at workshops, but stopped going to work for some reason or another. With nothing anymore to do, they started roaming around in convenience stores or supermarkets, causing complaints from the neighborhood as suspicious persons.

One woman used to commute on her own, but became depressed at one point and sometimes takes off her clothes.

Some developed self-assertive behaviors, confusing the entire families.

In one case, the father got sick and the mother is working. The brother who was providing care was arrested for shoplifting, and the mother is in deep trouble.

Those cases make me realize the extent of trouble for families, and the necessity of services to stabilize their lives.

However, I have seen some cases in which needs of family members and those of the user are not exactly consistent. I think that welfare services should eventually satisfy wishes of persons with disabilities themselves.

While the independent living assistant program is basically to serve for wishes of users, we are also providing support so that the users can identify what they want when they are not sure, express wishes with words, be responsible for what they say they want, and become able to live socially in the community.

It is very important to learn skills such as how to use money, cook, and do laundry and cleaning in order to live in the community, but in many cases persons with disabilities make excuses for their weaknesses or blame others, which has adverse effects on work and human relations, and in turn makes it harder for them to live. Considering the difficulties of support for independence as well as the fact that the abilities, regardless whether good or bad, acquired in growing up will be tested when living in the community, I reappraise the value of the daily life itself these days.

## ***Foreword***

*When being born to this world, nobody can choose how his/her face, hands or legs would look.*

*Nobody can choose parents, either.*

*All babies are born with no given choice.*

*In spite of that fact, people are judgmental: good, bad, pitiful, or troublesome.*

*Just because of “disabilities” . . . .*

*If his/her own mother is one of those people, then, how can it be possible to “keep going”?*

*“You are the mother, so you are responsible.”*

*If you feel like being accused by the society, here is the message for you.*

*“It’s not your fault, or your baby’s for that matter.*

*Be confident,*

*because your baby is strong enough to live*

*without even hiding his/her vulnerability or immaturity.”*

*Just the way it is, it’s fine.*

*You can cry if you want to.*

*Try asking your neighbor, “Can I use your handkerchief?”*

*Feel the warmth of the reached hand, and regain your humanities.*

*A life with more happy things than sad things is in your heart.*

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