

Ilse Achilles

## **Main Obstacles on Our Way to Friendship, Love and Partnership**

Ladies and Gentlemen,

it is a great pleasure to be here and to be able to talk to you and to listen to your experiences and opinions. Thank you for the invitation.

Let me tell you some of my experiences. My son is 44 years old. He has been living in an institution for about 20 years. He feels **at home and comfortable** there, but spends most of the weekends and the holidays with me and his sisters.

32 people live in the institution, 8 people in one group. Everyone has a room of his own. They work in the nearby **sheltered workshop**.

About 12 years ago a woman and a man, who lived there, **fell in love** with each other. They decided to live together and with the help of the very liberal staff they changed their rooms into **one drawingroom for two and into one bedroom – also for two**. No problem.

After a year, living together in harmony, they decided to get married and have a nice big party.

Since the parents of the woman and the man were dead, both had a support person each. These persons along with the staff **tried to figure out**, whether our couple had the **legal capacity** to get married. After all a marriage is a **binding contract** with a lot of **legal consequences**.

While these people talked to officials of the **registry office** and the **district court** there was a getting-together of parents and staff, which were regularly held at that time. Normally the main topics of these meetings were lack of cleanliness, lack of leisure facilities, improper nutrition (too fat, too sweet) and sometimes the **incompetence and the high sickness-rate** of the staff.

However, this time nobody talked about any of these subjects. Some mothers and fathers had heard that there was a couple that wanted to get married. A **big discussion** started. The main claims were: They should not be allowed to marry, because

1. This has never happened before;
2. All the other inhabitants would feel jealous and sad and it would break their heart to see two people happy, while they did not have a friend or - beware – a lover.
3. The partnership between these two handicapped people would not last anyway. It just causes stir and unrest for nothing.

The manager of the institution was **perplex**. He could not understand the violent reaction of the parents. Nothing much would change. The couple concerned would continue living as they lived already, sharing bed- and drawingroom.

This story shows the first of three main obstacles on the way to friendship, love and partnership. **It is the overprotection of parents**. We – and I include myself - want to keep our child from all sorts of pain, from lovesickness, broken heart, disappointment, rejection.

And, of course, sexuality frightens us. We do not want our child, grown-up as it maybe, **get entangled** in the traps of desire, passion, longing, love-madness. Okay, we agree that love and sexuality is part of **human life**, we know it even is a **human right**, but we do not want it for our children.

We do not realize that love and sexuality, even if it ends up in tears and disappointment, can **help to form a personality**, making people more **mature and selfdetermined**.

**Parents who try to stop their grown-up daughters and sons from having these experiences do great harm to them.**

We should not forget: Everybody has the **right to make mistakes**. People with intellectual abilities as well as people with intellectual disabilities. Thus the argument: „The partnership will not last“ is **no valid argument**. So-called normal people fall in love, suitable or not, engage, get married and **divorce** a couple of years later. Handicapped people have the same right. They can choose a wrong partner – as many people without a handicap do. They can separate – as many non-handicapped people do.

The main task of parents is to bring up their child to be an honest, self-respecting person, who **enjoys life and dares to make his choices**.

„**Selfdetermination**“ is big thing in Germany, but sometimes it means a person can just choose between a red and a green pullover. More **vital decisions** are done by **parents or support persons**. Did my son have a

choice when he moved into the institution, which I had found for him? No, he had not, because it was the only institution I could find at that time. Did he have a choice with whom he wanted to live in such a close group? No, the institution's manager decided who should join which group, according to the severeness of their handicaps.

Back to my story: What about the staff? They can be a very sturdy obstacle on **Our Way to Friendship, Love and Partnership**. Here, luckily, they did not object to these two people living together and having sex - being married or not.

Were they really that liberal? In parts, yes. They knew, however, as I did, that the woman concerned had **been sterilized** when she was a young girl.

Most probably they would have been less liberal if they had to be afraid of a **possible pregnancy**. Generally, German institutions are not at all prepared to have a pregnant woman in the house and later on to help and take care of mother and baby. They need special institutions, which we have in Germany, but **not sufficiently**, where mother and child and - if present – the father too, can be looked after properly. Where they can live **as a family** given special room and special support.

Generally, the staff, trained in special care and education for handicapped people, cannot give this challenging support. It is a most difficult task to help to care for a baby without causing **jealousy of the mother**. It requires **additional psychotherapeutic education and training** for the staff to handle this special situation, which lasts sometimes for months, mostly for years. That is why the support persons often try to **prevent** flirting, friendship, love and sex in an institution. They do not want to **complicate everyday life**.

Most of the staff in Germany is very good. They take their work seriously and care as well as possible for their entrusted, who now – by the way – are called „**customers**“. Which I find, to say the least, **ridiculous**. My son is no customer. He has hardly any money of his own, he has very few choices, so what can he buy? He is an entrusted, a person, who needs **support** in many ways, **no supermarket** for unfulfillable wishes.

Some of the staff, however, do **just their job**, they are **not dedicated** to the people they should care for, they do not see the special needs of their entrusted.

They work **early shift**, that is from getting up in the morning, until the inhabitants go to work at 7:30. Or they work **late shift** in the afternoon, when the inhabitants come back from work, until they go to bed. These are mostly less than 20 hours a week. Their pay is **not enough to make a living**. Thus

most of them take up a second job. That makes some of them overworked and tired. These conditions have to change. People who work with handicapped people should get **better payment. And more appreciation!**

Now, what about our couple? They were finally told that they were **not allowed** to marry because of intellectual disability. Were they downtrodden, disappointed, extremely unhappy? No, they lived on as before. And **they did it – their way**. No marriage? OK, they decided to have an **engagement party** instead, with white dress for her and black suit and silver tie for him, bridal bouquet, a horse drawn coach even. And the **parish priest** came to give his blessing. A great event, a big party, for everybody!

They succeeded because **they persisted**. They did not make the mistakes that many people with a handicap do. Most of them give up when obstacles arise. These two did not. They **had a dream** and they made it work.

That is exactly what we need on our way to **self-determination, to love and partnership**. **Parents** who let their grown up children go into their own life. **Staff** that is altogether more dedicated to their difficult tasks, **men and women**, who in spite of their intellectual shortcomings dare to stand up for themselves.

During the last 10 to 15 years there has been a lot of **empowerment**. Many clubs, confederations, groups for support of all sorts were formed. Very good. A big **signal of hope**. „Europe in Action 2017“. Keep on the good work.