

Empowering People with Autism. The Effect of an Integrated Daily Structure as Well as Improved Communication on the Lives of People with Autism

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Abstract

The main objective of this study is to analyze the quality of life of autistic adults in the practice of the human service. Classical models for dealing with people with autism were the initial position for developing a long-term intervention program for this client group. The aim of this intervention is to improve upon the quality of life, derived from studies of Schalock und Verdugo [1], by structuring their day to get orientation and by improving their skills to understand and to use basic communication structures. The program is constructed step by step. The first is to understand simple communication structures with gradual increase in complexity. The second is independently using the newly acquired knowledge to communicate and understand more complex structures. Daily observations are recorded in writing. In addition, assessment sheets are used. Each proband items were defined which were trimmed to capture for individual behavior and were scored several times a day. Our hypothesis that the quality of life of our autistic probands can be increased by enhancing them to understand communication structures and to use these structures for their own needs was confirmed by the results. Negative behavior like aggression which stands for low quality of life could also be decreased as a result. Self determination and inclusion also increased as a result of handling more communication structures.

Keywords

Autism, Quality of Life, Adults, Long-Term Study

1. Introduction

The Lebenshilfe Vorarlberg takes care about 900 clients with cognitive and/or physical handicaps. About 40 clients are people with autism.

In 2007 the institution started to look for ways of improving upon the quality of life for people with autism and found that a structured lifestyle with some basic communication skills plays a very important role.

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One of the reasons for this study was that the caregivers had to be capable of managing the difficult aspects of behavior of these autistic people—these difficult aspects do stand for low quality of life. Aggressiveness, constraints and dysfunctional communication increased the fluctuation of the caregivers and affected the behavior of the autistic client adversely. Maskey *et al.* [2] reported in their study that children with Autism Spectrum Disorder (ASD) have often four or more behavior difficulties like eating or sleeping problems, self injuring or sensory problems. These findings were consistent with the numbers of atypical behavior of our autistic clients at the beginning of the present study.

The caregivers do their work at the point of intersection between social structures and individual needs. They have to support their clients and also improve upon the quality of life of handicapped people. In this regard, questions arose as to what human service institutions do improve the lives of their clients and how the effects of their efforts can be assessed. The answers to these questions must be seen relating to international concepts of quality of life [3].

The caregiver's work affects the quality of life of the client, especially the quality of their social interaction and the personal care [4].

Most people grow up with their family and by this way they learn important social rules and skills which enable them to live in social communities as equal participants. For children with ASDs, this process is not automatically activated [5]. Dysfunctional communication and aggressiveness complicate social integration.

2. The Aim of the Study

The aim of the study was principally to improve upon the quality of life of people with autism by improving their communication structures, by enhancing them to apply other ways of communication independently and also by structuring their day in a visual way. Dominick *et al.* [6] noted a relation between the number of atypical behaviors and low expressive language in children with ASD. In addition, atypical behaviors such as self-injurious, aggression or temper tantrums are related to the severity of social impairment and repetitive behavior.

It was also an aim to qualify the caregivers in their daily work with the knowledge that well trained people can do this kind of job for a longer period. Furthermore, the second approach should help to decrease the fluctuation of the caregivers and contribute to a stable environment for the autistic clients as the caregivers try to enhance the autistic clients by applying the new ways of communication independently.

The more support the autistic subjects need, the higher is the influence of the caregivers on the quality of life. The support is useful if the recipients evaluate the caregivers work as useful [4].

3. The Study Participants

Research into adulthood is still less than about autistic children. Studies about children with ASD published numerous during the past twenty years [7]. All of the six study participants are male and everyone has a diagnosis within the autism spectrum disorder. The diagnosis of all participants comprises an atypical autism diagnosis and intellectual disabilities. The age range was 19 to 41 years at the beginning of the study.

The diagnostic criteria of autism spectrum disorder as it is described in the DSM-5 [8] were met by the participants in different dimensions: 1) All of the probands have persistent deficits in communication and interactions with others. They have problems for example to follow general communication rules, to understand the (emotional) meaning of a conversation or to get in contact with other people on a normal way. 2) All of the participants have "Restricted, repetitive patterns of behavior, interests, or activities ..." [9]. The values und ranges are individually different, but every one of the probands has a deficit in handle routinely changes. 3) From the medical history it is apparent that their developmental disorders were recognized in earlier childhood. 4) The impairment is clinically significant. 5) Although every participant has also an intellectual disability their symptoms are not better explained by another disorder category.

All probands are integrated into a daily structure and five participants live in different located shelters with other people with special needs. The homes hold various groups comprising of units with three to eight clients. Small groups enable the caregivers to be more responsive to the individual needs. The daily structure means that groups of four to eight clients work together from 8 a.m. to 4 p.m. Their work is a kind of occupation therapy without pressure to perform. They work in different day care centers within different work areas. Although there is no pressure to perform, the caregivers try to promote the skills of the clients.

4. The Quality of Life Concept

The qualities of life concept with which we operate upon in this study were defined by Schalock and Verdugo [1]. It is a multidimensional concept and takes into account subjective and objective criteria. They determined eight core domains of quality of life assume that people with and without disabilities have the same core domains. The authors emphasized also the importance of the context within which the client lives and interacts. Schalock and Verdugo [1] described three levels of context—the micro-level, the meso-level and the macro-level. The micro-level contains personal growth and development opportunities. On meso-level, the reflection of the interaction between the person himself and the environment is the center point, it concerns the functional assessment. The third level, macro-level, contains the social indicators.

The eight core domains are as follow [1]:

- *emotional well-being: e.g. satisfaction, contentment, feeling of well-being, mental health status;
- *material well-being: e.g. standard of living, savings, possessions;
- *interpersonal relations: e.g. intimacy, friendships, social supports;
- *personal development: e.g. adaptive behavior skills, activities of daily living skill;
- *physical well-being: e.g. health status, mobility, food and nutrition;
- *self-determination: e.g. autonomy, personal control, choice, allowance for choices;
- *social inclusion: e.g. accepted social rules, circle of friends, participation opportunities;
- *rights: e.g. privacy, ownership, personal freedom, due process, access.

5. The Intervention

Following the classical models for dealing with people with autism, methods were introduced which were designed to take into account the mental state of each individual. The different programs were necessary because of the uniqueness of each participant and their behavior.

One of the classical models is Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) which was developed by Eric Schopler [10] in the 1970s. The individual person with his strengths and weaknesses is the center point. From that base different supporting programs help the client to organize and structure the environment and to allow an adequate perception of it. Schedules, work systems and other visual cues and plans are used [11].

We also used Applied Behavior Analyses (ABA) which originates from the field of behavior therapy. On operant conditioning ABA tries to increase social behavior and to reduce inappropriate behavior [12].

The third model we used was the Pictures Exchange Communication System (PES). When the client hands over a symbolic object to the caregiver he obtains the real object. Due to action replay the client learns on how this system works [11].

The intervention program is a step by step system (**Figure 1**) and hierarchically organized.

The clients had to understand the first level before they could switch to the second. The basic point of the start

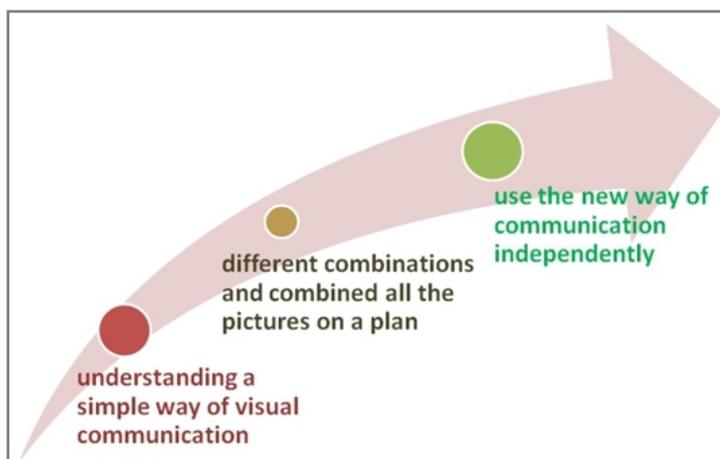


Figure 1. Course of the intervention program.

line was different and based on the skills of each individual. To motivate the autistic client it was necessary to know what they can and where their limits are. The caregivers had to be careful not to overtax the probands.

The first step of the intervention program was to enable autistic people to understand a simple way of visual communication. This means for example, to understand what a picture shows. For some of the autistic clients the caregivers used pictures (abstract illustrations) and for some they used photos.

The caregivers carefully initiated the communication between them and the autistic people. This necessitated a special training for the caregivers on how to handle the communication objectively. In the beginning they only used singular pictures.

When the autistic client understood the single pictures, they can serve as a visual communication system for example to show the client what is coming next or what he has to do now. The caregivers made different combinations and further combined all the pictures on a plan to create a visual illustration of the day structure.

It was also a step by step learning process to understand a daily plan. In the beginning the caregivers put only two or four pictures for a short period on the plan. They wanted to prevent overtaxing the clients with a multiplicity of pictures. First, the proband had to learn that there is a special sequence on how to use the pictures. On the second step they learned that a new visual activity can only be started when the previous had been finished. For some, one sequence was repeated frequently because they did it wrong or inaccurately. It was necessary to motivate them to do it right.

During the second main-intervention they should learn how to use the new way of communication independently. The caregivers tried to steadily enhance their ability to handle more complex communication structures. They should learn how to communicate their needs or show them when they are ill and have ache.

6. Methods

The institution Lebenshilfe Vorarlberg has a special database which can be used by each caregiver in each structure, home living and work area. It serves as a communication system and is used almost every day. The daily mood, special behavior (positive and negative), illness, interventions, etc. were recorded in writing since November 2005. The daily observations are divided into overall observation data and special or significant data, e.g. aggression, accident, missing person, etc.. The data can be evaluated by date, content or relatedness to the intervention program. Moreover, the institution has medical reports and mostly a comprehensive history report.

For the analysis of these comprehensive records we used MAXQDA [13], a special program for text analysis, which helps us to identify the systematic changes of special behavior.

In addition, we used assessment sheets. This instrument was also used by each caregiver in each structure of the client. The assessment items were individually defined. The individual forms of behavior of each autistic person were crucial for the choice of the items. Every item was scored 3 to 4 times a day. In the end the week averages were used for all further analysis.

7. Results

The results of our study show that the quality of life of the probands was improved by different communication possibilities and structuring. Four of the core domains were not influenced with the same intensity or not directly by the intervention program.

The core domain “rights” changed during the past decade because of the global change on the view of handicapped people. Although the changes must go on in the future some important right aspects are now better than before. Our probands are not able to discuss their rights because of their cognitive handicap but from an objective point of view, we can see the positive changes like equal opportunities on the labor market, in public areas, suffrage, etc.

The “material well-being” changed sometimes because of the possibility to communicate their needs and wishes, for example ice-cream or a book. Generally regarded, their social economic status changed also because of a global change on the view of people with disabilities. The opportunity to work and also to earn money creates in connection with self-determination the possibility to buy the object they want or the things they want to possess.

The “physical well-being” changed in a similar way. Some of the probands learnt to communicate their physical problems to the caregivers and so the caregivers could act correctly and in time. A reduction in medication was possible for five out of the six probands. Consequently, it may be assumed that the difficult aspects of behavior (aggression, strain) could be decreased by improvements in communication.

The study of Shipman, Sheldrick and Perrin [14] led to the result that autistic adolescent with normal intelligence are able to reflect on their quality of life and also on the deficit of the autistic disorder. In the present study the core domain “personal development” is very hard to evaluate because our probands cannot give us a verbal reflection about it because of their cognitive impairment. The evaluation of our study showed that the leeway of action and activity could be expanded although to different extents.

Therefore, the results show that the other four core domains changed in a similar way and were significant for each proband. With the use of explicit examples, the following changes were observed.

The “emotional well-being” could be increased by improved communication and structuring the time. The day mood was significantly better after four years of intervention and also the aggression and mental strain could be decreased. The graphics of **Figure 2** and **Figure 3** show the trend in aggressiveness of one proband in 2008 and 2010 and the intervention steps. Low values mean low aggression and high values mean a longer period of aggression or hard aggressiveness.

The significant result is inter alia that the new intervention increases the aggressiveness for a short period at the beginning for one to three months, but decreases for a longer period. The average of aggressiveness (**Table 1**) shows a non-linear course but during the observation period of four years a steady decrease is evident.

It could be seen that the situations in which aggressions occurred before have been remedied through an improvement in the communication structure. To communicate about the same thing and to understand the meaning and the aim of the communication from the other person can lead to a relaxation of the situation and further increase the emotional well-being.

Relaxed situations and the understanding of certain social rules enabled our probands to get more in contact with others. The “interpersonal relationships” changed. Both caregivers and other clients with special needs have another and better view of the autistic persons and get in contact with less fear and uncertainty.

The “social inclusion” was also determined by the relaxed situations and better contact to others. The autistic probands get more possibilities to participate in shopping, excursions and so on. The social inclusion of five of the six probands is no longer dependent on the caregivers who can handle the difficult aspect of their behavior. Visual communication systems show the autistic clients which social rules must be observed.

“Self-determination” could also be increased by enhancing the autistic client to understand simple ways of communication and the consequences of a particular choice. The graphics (**Figure 4** and **Figure 5**) show the trend of urge behaviour. Low values mean less urge behavior.

Urge behavior could be decreased in four of the six probands. The autistic client can choose between two or more selections or show the caregivers autonomy in what they want. Urge behavior reduces with an increase in communication skills.

The results clearly support our hypotheses that improved communication and structuring improved the quality

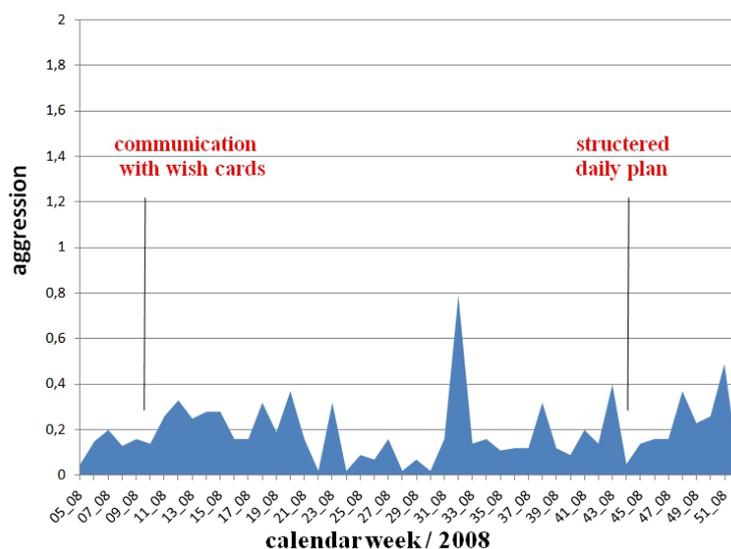


Figure 2. Trend of aggression and interventions 2008.

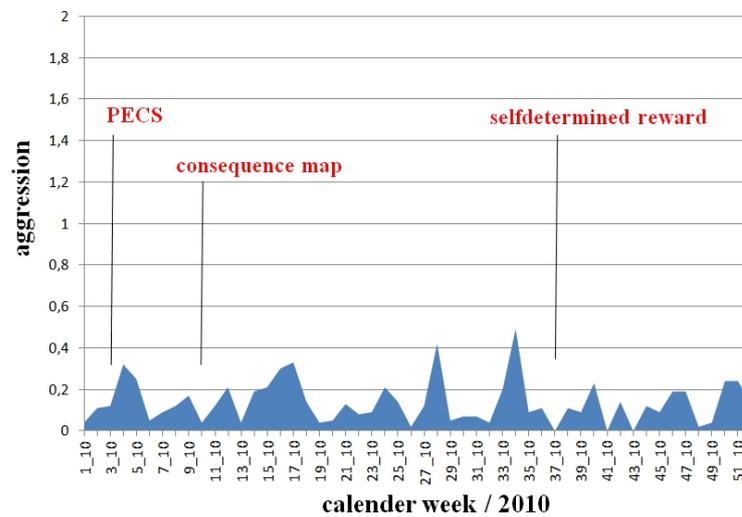


Figure 3. Trend of aggression and interventions 2010.

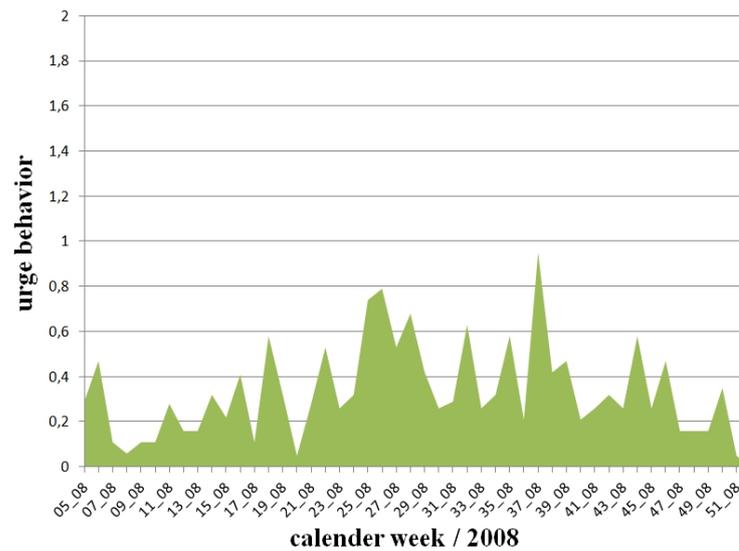


Figure 4. Trend of urge behavior in 2008.

Table 1. Average of agresiveness 2008-2011.

	Average/year	Minimum/year	Maximum/year
2008	0.19	0.02	0.79
2009	0.22	0.02	0.69
2011	0.13	0	0.49
2012	0.07	0	0.32

of life for the autistic probands.

8. Discussion

We started the basic framework and the Lebenshilfe Vorarlberg will carry on with improving upon the quality of life for autistic people using the new knowledge.

Our probands are all male. This study was conducted particularly for the male clients because they were more

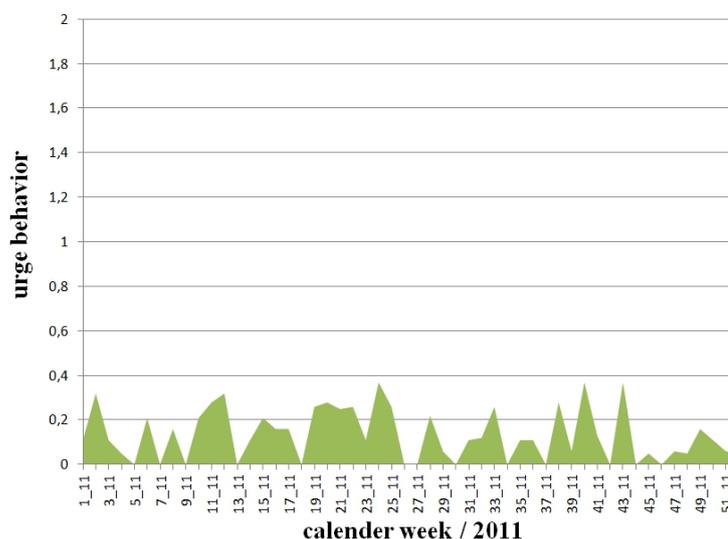


Figure 5. Trend of urge behavior 2011.

difficult to handle in our daily work which was shown by the data which were recorded in writing in the years before. But in recent past we included other autistic clients, independent of the gender or of behavior. The results are not yet available but will follow soon. The limited number of participants was right for the beginning because it took a lot of time and costs and made sure that a long-term study was possible.

As the study showed, a human service institution—especially the caregivers—can improve upon the quality of life of autistic clients. Behavior can change also by improving the human service and not only with medicine. Nevertheless it is essential that medicine supports other programs and brings the clients on a level on which they are accessible for further interventions [15]. It is necessary that all people within the social environment of the clients work together which includes relatives, caregivers, friends, teachers, doctors, etc.

In changing times, people of different walks of life have started rethinking the way they view handicapped people [16]. The transformation of terminology, for example, spread out to different areas such as politics, health services, social institutions, and called for an upheaval. Affected by them and partly because of the inadequate care situation our institution started with individual intervention programs to improve upon the quality of life. Essential for the success of these interventions was the individuality in the specialized programs. The different education for the caregivers qualified them to work out an individual intervention together with an external expert.

The specialized programs supported the autistic clients on their way to higher quality of life. The individual starting points, depended on their skills, were useful to keep their motivation and not to overtax them from the beginning. The promotion was based on the approach that positive experiences keep their motivation for a longer period. This approach was confirmed by the positive effects after teaching them with rewards. The benefits and the positive effects cannot hide the fact that new interventions increase the negative aspects of behavior at the beginning. The result shows that continuous promotion and the demands of well-trained caregivers end in a more relaxed situation, for both.

Although our clients cannot reflect their thoughts because of their cognitive handicap, we can read their behavior and interpret less negative behavior as an increase of wellbeing. Aggressiveness, urge behavior or constraints are also uncomfortable and negative for the executive clients. The learning process created a situation in which the probands did not know first what they had to do. In such situations, frustration occurred and negative behavior was the expression of it. The more they learnt how to communicate and how to understand the structure, the less negative behavior occurred. Dominick *et al.* [6] also point to the possibility that behavior like aggression is the consequence of the inability of an autistic child to communicate for example his needs. Subsequently, the further learning process could be better communicated because of their increasing understanding of requirements.

These positive impacts affected first the core domain emotional well-being because they feel better with less strain, less aggression or less urge behavior. The day structure mediated a secure feeling and led to more orientation.

In further consequence, the other core domains are covered by this positive effect. The autistic client realized that they can have an impact.

Interpersonal relations can arise or grown up without fear, instead of an accompanying fear from the autistic client of unknown situation and incomprehensible demands and fear from the other people of the negative behavior. To understand social rules with a high quality of communication enable the clients to act correctly and less conspicuously.

These effects influence the rise of social inclusion and more positive activities within the society were possible.

Self-determination grows up because of the opportunity of choice and the ability to tell the caregivers what they want. The communication system enabled the autistic probands to inform the caregivers about their wishes and be sure that the other person understands what they say.

To enable autistic people to understand their environment and to communicate with others affected their quality of life in a positive way. To find the individual way to enable autistic clients to get in contact with others in an adequate way could be one of the culminations in supporting people with special needs.

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