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SMMCO

Support Module
for Management of
Care Organizations

READER SUPPORT MODULE MANAGEMENT OF CARE ORGANISATIONS

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Chapter 1

Context Module for Managers of care organisations

Managers of care organisations are facing nowadays many issues they have to deal with.

Recent years much attention is given at a person centred approach, which means that persons who are depending on care are the central persons. This development is in line with the UN Convention on the Rights of Persons with disabilities and the European Disability Strategy 2020 – 2030. These developments are based on a citizen paradigm in which the persons with a disability need to be treated and respected as a fellow citizen with all the citizens rights.

Many managers of care organisations are providing care services which are not fully in line with this paradigm. Providing services from the citizen paradigm has consequences for the organisation structure, management style, culture and competences of care professionals. All are connected, one cannot without the other. This means that providing self-directed support can e.g. only take place when the structure of the organisation make that possible and that the competences of the care professionals fits with support oriented care. It is not a question **if** these changes are needed. It is a question of time that these changes must be implemented. Developments in society will demand this.

Another important issue managers have to deal with is the cultural aspect. This is not only linked to the style of management, but also related to how persons with a disability are treated., relations among care professionals etc. Nowadays there is also a growing awareness that employees of organisations must be able to work in a diverse, inclusive and adapted work environment. This also reflects the professional workers in the care sector. It is important to address this, also due to the situation that it is important that care professionals maintain their job, that they are not leaving. There is a high demand of care professionals.

For managers it is important that they are aware of these developments and that they acquire knowledge about the necessary steps to transform their organisation into a support oriented care organisation with professional support workers. All these aspects shall be addressed in the Support Module for management of care organisations.

This Reader is background information and is related to 14 Requirements which shall get attention in the Training Module

The Module is designed to give an insight and develop knowledge about the roots, connected theory, attitude, tools and research around Support. Combined with this practical casus related to organisation design, management style, implementation of support services and facilitation of support professionals shall be included in the Module

Criteria's

The criteria's to attend the module are based on research which shows that the human right of people with a disability are still neglected or do not have the same opportunities as "non disabled people" (Basis human rights 1989, convention of Vienna)

The basis are ***Performance Requirements (PR).***

1. Definition and discussion of Support and its essential elements
2. Client centred therapy (Rogers) and the four dimensions of care (Tronto) in relation to the essential elements of Support.
3. The roots of social exclusion and the mechanism of continued segregation in our society.
4. The role of a Support professional.
5. Description and discussion of the necessary attitude of the Support professional.
6. Description and practical examples of presents and participation in the community of so-called "redundant" people using the accomplishments of John O'Brien.
7. Description of types of integration (physical, functional, social).
8. Description and discussion about the relationship between the Human Rights Convention and the essential elements of Support.
9. Description of the paradigm shift (development from Institutionalisation, de-institutionalisation to Support).
10. Elements of de-institutionalisation compared with elements of Support
11. Description of organisation structures, competences and management styles.
12. Structure and Culture of Program-oriented care versus demand-oriented care
13. Essential differences between quality of care and quality of life.
14. Description of the necessary conditions of organizational design of Support from a client's perspective and the organizational perspective.

Learning goals:

1. The student has (as manager) knowledge and insight into person-centred support provision
2. The student has knowledge of how to facilitate professional care workers to function as a support professional
3. The student has knowledge about the necessary organizational structure, culture, and management style of a support organization
4. The student has knowledge of the needed competencies of care professionals to enable them to work as support professionals.

Outcome:

The outcome of providing managers with extended knowledge of the subject behavior change will lead to an increase of people positioned in roles as support professionals within the facilities of an organization.

The module is designed based on the Dublin descriptors which were drawn up to provide an equivalent level of education in European countries. Therefore measurements of criteria are valued throughout the countries. The Dublin descriptors focus on:

- knowledge and insight
- applying knowledge and insight
- judgment
- communication
- learning skills

The Dublin descriptors are created in tables of importance and level of education. Therefore they are designed for the following levels: associate degrees, bachelor level, and master level.

This table provides equal opportunities for all participants of the modules provided.

Support Module for Management of Care Organisations

	Time	**Learning objective(s)/ issues to address**	**PR**	**Training activities/ resources** (to be defined)
1st session: 1st hour; 2nd hour	50 min + 50 min	Introduction of participants and training. Building a shared vision on SDS Definition: • Discussion of SDS and its essential elements - individual choice of the citizen at the organisation or centre; • Client centred therapy (Rogers) and the four dimensions of care (Tronto) relation with SDS.	1, 2	
2nd session: 1st hour; 2nd hour	50 min + 50 min	The Roots of social exclusion and the mechanism of continued segregation in our society. Description of types of integration: • Physical; • Functional; • Social.	3, 7	
3rd session: 1st hour; 2nd hour	50 min + 50 min	John O'Brien: • Introduction; • The five accomplishments. Relation of SDS and the international frameworks: • UN Convention on the Rights of Persons with Disabilities; • Sustainable Development Goals (SDG); • Empowerment + auto-determination & citizenship + inclusion. Advantages and challenges of SDS.	6, 8	
4th session: 1st hour; 2nd hour	50 min + 50 min	Description of the paradigm shift: institutionalisation, de-institutionalisation, rights-based approach. Comparing elements of de-institutionalisation with elements of SDS.	9, 10	
5th session: 1st hour; 2nd hour	50 min + 50 min	Self-assessment: • Structure and culture of programme-oriented care vs demand-oriented care; • Organisation structures, competences and	12, 11	

		management styles.		
6th session: 1st hour; 2nd hour	50 min + 50 min	Self-assessment: - Role of a support professional; - Necessary attitude of support professional.	4, 5	

6th session: 1st hour; 2nd hour	**50 min + 50 min**	Self-assessment: - Role of a support professional; - Necessary attitude of support professional.	**4, 5**	
7th session: 1st hour; 2nd hour	50 min + 50 min	The necessary conditions of organizational design of support from client's perspective and organizational perspective. Essential differences of quality of care and quality of life.	13, 14	
8th	50 min + 50 min	Group final presentation. Module evaluation (satisfaction).		

After the module, you are able to:

1. Show knowledge and insight in person-centred support provision
2. Facilitate professional care workers to function as a support professional
3. Have knowledge about the necessary organization structure, culture, and management style of a support organization
4. Have knowledge of the needed competences of care professionals to enable them to work as support professionals.

Chapter 2 (PR 1)

Definition and discussion of Support and its elements

Introduction

In support, the directing role lies with the client. The client must be equipped in such a way that he can actually fulfil this directing role.

The support employee is supportive and will draw up a personal plan based on the client's direction. The topics that can be covered are countless.

They are based on the interest and capabilities of the client. An important outcome with support is that the support and guidance is offered, based on the client's own choice, which makes it possible to participate in society. The emphasis is placed on promoting the capabilities of the client

Support can be seen as a broad form of support and guidance in different areas of life of an individual, usually vulnerable, person who needs this form of support and guidance to be able to work, among other things. are in society and to be able to participate in it

Wiese[1] points to the broad aspect of support and gives the following three aspects

1. Support is supported on demand, where the client is in control, supported if necessary by the people close to him;
2. Support is a method of support that maintains and promotes the self-determination of the client as much as possible
3. Support shall be a method of support in such a way that:
    - as much as possible a happy life is promoted by: being able to make your own choices, having control over your own life, being able to develop and learn experientially, being able to enter into relationships, being able to come to ordinary places in society and being a respected citizen in society.
    - as little as possible a happy life is limited by: your physical and psychological condition and health, your living environment, your personal factors, the norms and values of the support staff, the stay in a form of housing, living in a group and the structure, processes and culture of the organization

The pillar of support concerns the belief in universal values, so applicable to every human being. Universal values that have to do with equality (human) dignity, freedom (of thought), but also happiness, love, respect, and justice

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[1] Ad Wiese. Demand-driven support for people with intellectual disabilities. Publisher: Nelissen, Soest 2006, ISBN 90244 17635. Ad Wiese. Vraaggestuurde ondersteuning van mensen met een verstandelijke beperking, pag 146 en 147. Uitgeverij Nelissen. Soest 2006. ISBN 90 244 17635

John O'Brien[2] mentions 5 core values that are essential to actually give substance to support.

These are:

- participating in society;
- be able to enter into relationships with others;
- be treated with respect;
- be able to develop their own possibilities / contribute to society;
- be able to make your own choices

Role of Society

A status of disability had the impact that there was no focus on abilities, but on the limitations. The effect of this all was and still is that in many situations, persons with a disability experienced isolation and barriers in functioning in daily life. For many years the persons with a disability were, and in many situations still are approached from a " medical" model. The medical model assumes that the disabled person's autonomy is limited due to the impairments. Therefor when the medical professionals cannot cure or rehabilitate the persons, then he or she is considered as someone who have as a consequence a limited ability to participate in society. Social exclusion is an effect on that, the exclusion of people. Further it also reinforced the disabled person's dependency.

In an economic way persons with a disability were valued less, due to the fact that they are not economically productive or do not appear to be. The result of this was not only financial inequality but also social inequality.

As a reaction on this inequality the "social model" has been developed. Instead of focussing on the impairment itself, the social model focusses on society being the cause of the problem with disabling the individual.

In order to understand the social model, it is important to distinguish "impairment" and "disability". Impairment is attributed to functional limitations characterised by a physical or mental impairment. Disability is linked to the loss of opportunities in society caused by societies failure to break down the barriers (physical and social), which hinders participation in society.

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[2] From Certificate Program in Person Centered Planning, Module I en II. Program on Employment and Disability. Cornell University, Ithaca. 2001

The social model is focussing on breaking down barriers. At European level the European Parliament stated in the Resolution on the European Disability Strategy post 2020 that all persons with disabilities have equal rights in all fields of life (inclusion and access to an open labour market and education) and are entitled to in alienable dignity, equal treatment, independent living, autonomy and full participation in society, respecting and valuing their input to the social and economic process of the European Union, whereas more than half of the member states are depriving people suffering from mental, health problems or with an intellectual disability of their right to vote.[3]

The focus on breaking down barriers is an important step forward. By looking at what persons **can do** instead of what they can't do gives perspective. This does not say that accommodations should not be needed, in the contrary they are needed to facilitate persons to get included and be able to participate in society. For care organisations are these developments important. Not everything needs to be on the shoulders of care providers. No longer taking care, beside care related to the impairment, of everything, but supporting, facilitating and stimulating inclusion and participation. This also means that in society many changes are needed to make these developments possible.

Self-directed Support

A growing attention is given at Self-directed Support. Self-Directed Support (SDS)is a way of providing support that means people are given choice and control over what kind of support they get. It means people can choose and arrange some or all of their own support instead of having it chosen and arranged by other people. It is not the name of a particular type of support service, but a way to make sure that care and support is better suited to the people who need it.[4]

Self-directed Support is the name for a system of support that puts people in control of their support and means:

- Confidence – people know their voice will be heard
- Control – people shape their support to fit their own life
- Connections – people grow strong relationships of love and power
- Contribution – people share their gifts and help create a better world (Self-directed Support Network).

The aim of Self-directed Support is to promote independence by offering more flexibility in how services are provided to people who are assessed as being eligible for social care support.

Self-directed Support enables people to take more control over decisions which affect their lives. It is intended to support independent living by giving people more choice, control and flexibility over their own care.

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[3] Motion for a resolution B9 –0123/2020 accepted by the European Parliament

[4] Self-directed Support: A Guide for Carers. ISBN 978-1-78412-513-8. The Scottish Government, June 2014

Chapter 3 (PR 2)

The Client approach

A client approach goes back to the ideas of Carls Rogers and Joan Tronto.

3.1 Introduction

Rogers[5] ideas are based on a client -oriented approach in which he wants to express that in a therapeutic relationship the client, as a unique individual with his thinking and feeling, should be central. The client must indicate, based on his ability to develop positive development and development, how and where improvements can take place. For the client, the therapist only creates the conditions for further development.

In the opinion of Rogers about the development of humans, four starting points are central:[6]

1. Human naturally tends to realize individual possibilities present.

2. The experience is about reality as the person experienced this subjectively. This subjective perception is called perception. The focus on the subjective experience means that the person can only determine himself and express what his reality, his personal frame of reference, looks like.

3. Is the combination of principles 1 and 2: the behaviour of the individual is the targeted attempt of that individual to realize the experienced needs of self -realization, as he perceives it. The person develops in an interaction with reality.

4. As a result of self -realization, the individual will develop a coherent self -image, which in his experience is separate from the rest of the world: "I am aware that I am." The person experiences himself as a more or less equal to others in all kinds of ways, but at least as an independent individual that distinguishes himself from others.

According to Rogers, therapy must meet three conditions. [7]These conditions are needed and sufficient to make change in the person. They concern:

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[5] www.geneeskunde.net: about Carl Rogers. From clinical psychology, Chapter 7. Humanistic theories. Pubisher Wolters Noordhof.. ISBN 90 .01.596339. www.geneeskunde.net. d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Hoofstuk 7. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBN 90.01.596339

[6] www.geneeskunde.net: about Carl Rogers. From clinical psychology, pag. 3 and 4.. Humanistic theories. Pubisher Wolters Noordhof.. ISBN 90 .01.596339 . d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Pag. 3 en 4. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBV 90.01.596339www.geneeskunde.net. d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Pag. 3 en 4. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBN 90.01.596339

1. The therapist must be able to function congruent in his relationship with the client. The core idea in Rogers's client -oriented relationship is that the therapist - as an important person for the client - has to show a lot of unconditional positive appreciation, to compensate for the excess of conditional positive appreciation that the client has experienced in his life.

2. The therapist must meet the client with a maximum of unconditional positive appreciation. He must accept and respect the client as much as possible as a "person" with all his plus and minus points. The point is that the client feels accepted at a fundamental, personal level.

3. The third central point is empathy. The therapist must empathize with the maximum in the client's thinking and emotional world. He must also let the client show that he gives his thoughts and feelings as if they were his own.

The conditions mentioned by Rogers are in relation to each other.[8] In this way there is a relationship with the client of trust, appreciation, and understanding.

According to Tronto, care is a moral value[9] that must be expressed in the actions of people. Care must also be the starting point for the design of society. In the image of man image that, according to Tronto, is at the basis of a caring society, vulnerable dependence and self-reliant autonomy are equivalent and each other penetrating aspects of human existence.

3.2 The four dimensions of care

Tronto[10] sees care as a process that has different dimensions, i.e.:

- concrete care (care-giving);

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[7] www.geneeskunde.net: about Carl Rogers. From clinical psychology, pag. 10 and 11. Humanistic theories. Pubisher Wolters Noordhof.. ISBN 90 .01.596339 . d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Pag. 10 en 11. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBV 90.01.596339www.geneeskunde.net. d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Pag. 10 en 11. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBN 90.01.596339

[8] www.geneeskunde.net: about Carl Rogers. From clinical psychology, pag 11. Humanistic theories. Pubisher Wolters Noordhof.. ISBN 90 .01.596339 www.geneeskunde.net. d.d. 27-10-2008. Van der Molen e.a. over Carl Rogers. Uit Klinische Psychologie. Pag. 11. Humanistische theorieën. Uitgeverij Wolters Noordhof. ISBN 90.01.596339

[9] www.hiva.be. D.d. May 16, 2006. H. Maasschot, M. Verkerk. Ethics of care, pag 130. A discussion, Amsterdam, Boom 1994. www.hiva.be. d.d 16 mei 2006. H.Maasschot, M.Verkerk. Ethiek van de zorg, pag. 130. Een discussie; Amsterdam, Boom 1994

[10] Joan Tronto: Moral Boundaries: A Political Argument for an Ethic of Care, New York, Routledge, 1993

- worry about (caring about): paying attention to the fact that care is needed;

- caring for: acceptance of the responsibility that care will be given;

- receiving care (care-receiving).

The dimensions cannot be seen in isolation from each other. The attitude of the care provider, but also that of the care recipient play a role. It also concerns the interaction between the care provider and the care recipient. They meet. The attitude towards each other is important. It is important that the person who receives care is treated with respect.

There are different actors within healthcare. These include the care recipient himself, the care provider, the care provider and the financiers of the care. Each of these actors has a specific role and responsibility.

Questions that play a role in the provision of care include:

- is the requested care provided?
- What is the role of the care recipient?
- Are there any restrictions in the provision of the care?
- Are there any restrictions in funding that prevent the indicated care from being provided?
- does the client want the care that is offered?
- What is the attitude of the care provider?

Tronto defines good care as giving and receiving care in an attentive, responsible, competent and responsive manner. The four dimensions underline the character of care, as a process in which several stakeholders at different levels play a role. The various responsibilities may conflict with each other, as can be deduced, for example, from the questions mentioned above.

3.3 Care virtues

Tronto introduces four care virtues (care ethics) that must play a role in the way in which the caregiver / supporter in care performs his task.

These four virtues of care concern:

- Attentiveness: attention/alertness
- Responsibility

- Competence

- Responsiveness

Attentiveness: attention/alertness

Is the ability to suspend your own goals, ambitions and worries to be able to show interest and to pay attention to others.

Responsibility

Is providing care when you signal that there is a need for it and there is no other way in which that need will be met.

Competence

Is the complete capacity necessary to ensure that the intended care and the acceptance of responsibility will lead to the provision in the need for care.

Responsiveness

Means that you can deal with your own vulnerability and inequality when receiving care and vice versa that you can deal with the vulnerability and the inequality of others in providing care.

3.4 Support oriented care giving

From the history, the dilemma of the supply -oriented care and the dominance of the care assistant lies in care. Many care assistants are of the opinion that they are experts and that they therefore know what is good for a person with disabilities.

When offering support -oriented care, the person with a disability is central.

The support employee will have to focus on the person with a disability. This is a unique person with wishes and possibilities. At the individual level, the care demand of the person with disabilities will have to be portrayed. This process is also about obtaining a correct picture. It is important that it must be about the question that the person actually has. It should not be forgotten that many people with disabilities have functioned to a large degree of dependence. Their attitude and behaviour are tailored to this. Choices were determined by the care provider. There are many examples of situations where the person with disabilities were asked the question, and, before an answer was given, the care provider was looked at. Also, even in the presence of the person with a disability - there have often been questions and discussions about the person with a disability without the questions being directly addressed to the person with disabilities.

Many people with disabilities have a limited frame of reference. Because they themselves have functioned in a limited environment. That means that they might want to make other choices if they knew what they could choose. For many people, by gaining new experiences, new possibilities come into the picture. This is no different for people with disabilities. Support can be aimed at offering experience options. New experiences offer space for new choices.

After the demand for care has been portrayed, it will have to be determined how support can be designed. The demand for care must be translated into a care plan with a associated plan of action. The action goals are described in the action plan and it is indicated how work is being done on the realization thereof. In the concrete implementation of care, the problem can argue that the support employee tends to do activities for the person with a disability himself. Support also implies respect for the autonomy of the person to whom support is offered. Support means in this context: "no more than necessary and no less than necessary". In concrete terms, that means that a person with a disability is in the foreground. The support employee is the shadow that supports the support where it is needed.

3.5 Rogers, Tronto and Support further highlighted

Both the views of Rogers and Tronto can be seen as precursors of the "support thought".

Rogers[11] states that every person naturally tends to realize individual possibilities present. This congenital tendency to self -realization is the driving force behind the development and development of man. Rogers did not call the person a patient, but a client. The client was assigned the active role. The independence of the client is emphasized. An independent individual who distinguishes himself from others. Rogers is based on freedom in the perception and experience process. The client can choose within a certain freedom of movement. This freedom of movement does not go so far that others may be caused by damage.

Tronto points out the connection in the four care dimensions. Care recipient and care provider meet. In this meeting there must be a respectful treatment. At Tronto it is mainly about the attention for the other. This is about compassion and compassion. There is a positive feeling to the other. Tronto has not gone so far that there should be any "restraint" when "taking care of". This means that care is provided as the care provider feels and sees it. Taking care of the client can withhold the client, as the care provider sees. As indicated, the client has the control. What important at Tronto is that space is created for "meeting". The

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[11] Ad Wiese. Demand-driven support for people with intellectual disabilities. Publisher Nelissen, Soest 2006, ISBN 9024417635. Ad Wiese. Vraaggestuurde ondersteuning van mensen met een verstandelijke beperking. Pag 149 en 150. Uitgeverij Nelissen, Soest 2006. ISBV 9024417635

care provider and the care recipient meet as people. Compared to traditional institute care, this is a clear shift, in which the person was seen as an "object". Rogers also recognized this and has opted for "client" instead of the term "patient".

According to Maas,[12] Support concentrates attention to people, on their possibilities, in place in the community and works equally with the client and his immediate environment on possibilities for this.

Support is a broad concept and can focus on all aspects of life of a person with a disability

3.6 Conclusion

Rogers and Tronto have contributed to people who are dependent on care. The care recipient was seen as "fellow human". Support takes this as a starting point and goes one step further. From a positive attitude, the emphasis is placed on the interest and possibilities of the person with disabilities. This has contributed to the fact that opportunities can be realized for the presence and active participation of people with disabilities in society. Realization in a way that they must be seen and accepted as fellow citizens.

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[12] Prof. C.W.Maas. Presentation: Support Working midel and training options, Tilburg 2008.Prof. C.W.Maas. Referaat: Support Werkmodel en opleidingsmogelijkheden, Tilburg 2008

Chapter 4 (PR 3)

Origins of social exclusion

This chapter examines the origins of social exclusion and the mechanism of continuous segregation in our society.

4.1 Introduction

Exclusion in society is also referred to as social exclusion. Social exclusion is seen as a form of discrimination. The policy of the European Community is aimed at combating discrimination on grounds such as disability and age. The legal basis is Article 13 of the Treaty of the European Community. The new United Nations Convention, the UN Convention on the Rights of Persons with Disabilities, also aims against discrimination against people with disabilities.

The general principles of this Convention are laid down in Article 3. This Article is formulated as follows:[13]

The respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and the independence of persons;

b. Non-discrimination;

c. Full and effective participation and integration in society;

d. Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity;

e. Equal opportunities;

f. Accessibility;

g. Equality between men and women;

h. Respect for the developing capacities of children with disabilities and respect for the right of children with disabilities to preserve their identity.

4.2 Definition of Social Exclusion

Schuyt[14] describes social exclusion as: “not belonging”, the cause of which can vary. It can be about: not being allowed to belong, not being able to belong and not wanting to belong.

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[13] Articl 3. UNU Rights Convention, December 2006

The use of the term social exclusion for certain social phenomena is relatively recent.[15] In the past, the concept of social exclusion was defined in relation to the concept of poverty. In the case of social exclusion, both the relational and the distributional dimension (both material and immaterial aspects) must be considered.[16].

Social exclusion refers not only to the process of being excluded (dynamic), but also to the actual state of being socially excluded (static). The causes of social exclusion can lie in the individual situation as well as in the environment.

Schematically, this can be represented as follows[17]

Conceptual model: risk factors and characteristics of social exclusion

Micro: persons/ housholds

Uncontrollable risk factors

- *Age*
- *Gender*
- *Marital status*
- *Family composition*
- *Social origin*
- *Ethnicity*

Modifiable risk factors

- Self-sustainability
- Health
- *Education*
- *Labourmarkt positon*
- *Physical and social living environment*

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[14] Gerda Jehoel-Gijsberg, Sociale Uitsluiting in Nederland, pag 16. Socuaal en Cultureel Planbureau, Den Haag, oktober 2004, ISBN 9037701604

[15] Gerda Jehoel-Gijsberg. Social Exclusion in the Netherlands, pag 15. Social and Cultural Planburo, The Hague, October 2004, ISBN 9037701604.Gerda Jehoel-Gijsberg, Sociale Uitsluiting in Nederland, pag 15. Sociaal en Cultureel Planbureau, Den Haag, oktober 2004, ISBN 9037701604

[16] Gerda Jehoel-Gijsberg. Social Exclusion in the Netherlands, pag 33. Social and Cultural Planburo, The Hague, October 2004, ISBN 9037701604 Gerda Jehoel-Gijsberg, Sociale Uitsluiting in Nederland, pag 33. Socuaal en Cultureel Planbureau, Den Haag, oktober 2004, ISBN 9037701604

[17] Gerda Jehoel-Gijsberg. Social Exclusion in the Netherlands, pag 39. Social and Cultural Planburo, The Hague, October 2004, ISBN 9037701604 Gerda Jehoel-Gijsberg, Sociale Uitsluiting in Nederland, pag 39. Sociaal en Cultureel Planbureau, Den Haag, oktober 2004, ISBN 9037701604

Characteristics of social exclusion

- *Deficit on social cultural dimension:*

a. *Insuffcient social participation*
b. *Insufficient normative integration*
c. *Deficit on economic structural dimension*
d. *Material deprivation*
e. *Insufficient access to "social rights"*

- *Lack of future prospects.*

Risk factor Meso level

Autohorities, companies, citizens

- *Inadequate execution*
- *Waiting times*
- *Financial thresholds*
- *Risk selection (by employers, banks etc.)*
- *Discrimination*
- *Stigma*

Risk factor government Macro level

- Inadequate policy
- Insufficient availability of facilities
- Insufficient access facilities

Risk facto social developments

- *Econimic recession*
- *Individualization*
- *Bureaucracy*
- *Urbanization*
- *Immigration*

4.3 History of social exclusion of persons with disabilities

The social exclusion of people with disabilities has a long history and is based on the way in which people with disabilities were viewed. Over the past hundred years, there have been three dominant views (paradigms) on thinking about the causes of disability.

Globally, this is shown schematically as follows [18]

	Phase 1	**Phase 2**	**Phase 2**
Central question	**Period of institutionalization**	**Period of de-institutionalization**	**Period of Citizenship**

Stage 1 is also referred to as the defect paradigm stage[19]. The defect paradigm is based on the individual human being with his limitations. The disabled person is first and foremost a patient in need of care. Man is seen as a biological object: an organism that may or may not have defects that can be remedied. If such a limitation means that someone can no longer comply with the accepted norms and values of society, it is considered a disability. Disabled people were admitted to institutions that were remote from civilization. Seclusion from society was considered necessary not only to provide proper care for the disabled, but also to protect society from disabled people.

Phase 2 is also referred to as the development paradigm. According to this paradigm, disabled people should be able to lead an existence as close to normal as possible. They are no longer sees as patients, but as ordinary people with special needs and development potential. This development has led to de-institutionalization.

However, little consideration was given to the wishes of people with disabilities. The basis of this thinking lay in the division into categories: people who need care and "normal" people. Also referred to as “normalization”. Normalization then comes down to: allowing the disabled to live in an environment following the norms of the “standard person”. Particularly during this period, the number of so-called specialized facilities in e.g. the Netherlands has grown strongly (within healthcare, within education).

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[18] www..cadenza.oc.nl drs Theo Wildeboer and drs. Rob Franke. Article "Where does exclusive thinking come from?". pag. 2 Magazine for inclusive Education, January 2006.www.cadenza-oc.nl drs Theo Wildeboer en drs Rob Franke. Artikel “Waar komt exclusief denken vandaan?”,pag.2 Tijdschrift voor Inclusief Onderwijs, January 2006

[19] L.Boekhoff and M.Kamp. Supported Employment. The role of the care sector, pag 5 and 6. Publisher Stichting Zuidwester, 1994. ISBN 90 802207-2-8. L.Boekhoff en M.Kamp, Supported Employment. De rol van de zorgsector, pag 5 en 6. Uitgave Stichting Zuidwester, 1994. ISBN 90 802207-2-8

4.4 Exclusion from social participation

In the period of Phase 1, the emphasis was on the disability. The isolation of people with a disability, in which they were placed outside society, as it were, did not contribute to fulfilling a role within society. Although the period of institutionalization is many decades behind us, there are still many remnants in the way care and services are offered to people with a disability. This mainly concerns the attitude of the care and service providers themselves, who function according to their “routines” and experience few incentives to change this. The organizational framework within which care and services are provided also continues to form an obstacle to the social participation of people with disabilities.

Phase 2 has brought people with disabilities closer to society. Special forms of housing have arisen and also in the field of daytime activities there has been more coordination with the "outside world", but then from specialized facilities. Disabled persons were dependent on special education and subsequently on work in an adapted environment (sheltered workshop) or in a day centre for the disabled. The institution did remain the safe base from which the activities took place. The orientation was also strongly inward. The facilities of the institution were used as much as possible. The work program of the institution was the basis for activities organized for the benefit of people with disabilities.

Emphasizing the special, the limitation/disability also meant that little or no consideration was given to the possibilities. The wishes of people with disabilities were not taken into account.

Persons with disabilities had to fit into the programs that were offered. These were programs that related to daytime activities, care and housing, among other things.

4.5 Developments in society

When finding a specific reason for excluding people with disabilities, there is also a clear relationship to social and economic developments. The industrial revolution has led, among other things, to the development of stable situations in the form of processes and procedures from the point of view of costs, effectiveness and productivity, among other things. This has also had an effect on the care sector, which started developing working methods based on protocols and procedures. Financing standards that were introduced are based on standard norms that have become the basis for implementation practice.

4.6 The change

In addition to a number of negative aspects, individualisation in society has contributed to the provision of space for the individual. Responsibilities were also shifted to the individual. The caring society had to give way to personal responsibility and initiative. Phase 3 fits into this picture. Personalization also means looking at possibilities. This has created space for people with disabilities. The Phase 3 paradigm is also referred to as the citizenship paradigm

The citizenship paradigm is based on the idea that a person with a disability can give shape and substance to his existence as an equal and fully-fledged citizen in society. However, due to his limitations, he needs support and guidance. The emphasis is on the principle of equality. People with disabilities have the same social needs as others, they have equal rights and should be given equal opportunities. The new United Nations Convention on the Rights of Persons with Disabilities is in line with this.

Many care institutions use “mission statements” which show that the person with a disability is central and that he is seen as the centre of care and service provision. It is also often stated that persons with disabilities have the right to participate in society.

4.7 The Dilemma

Many people with a (mental) disability have no friends and are dependent on care providers. The participation of people with a mental disability is also bad in many European countries. The mission statements of the care institutions have not operationally contributed to the realization of “citizenship”.

The schedule with the Phases stated under 4.3. gives the impression of a phased development. In practice, however, this appears not to be the case. The problem lies in the structure of the organization and the way in which care and services for people with disabilities are designed. For example, when realizing a new form of housing in the residential area, the general facilities in the residential environment department are usually not used, but the facilities of the care institution are used. The scheduling of care workers who are responsible for the care and services of people with a disability in these new homes is based on the organization and working method of the care institution, which has a strong inward focus. Also with regard to daytime activities, it is often not considered what possibilities there are in the immediate new living environment, but use is made of the range of institutions on offer.

The institutional characteristics are, as it were, applied to smaller residential units. The major disadvantage of this is that it reinforces segregation and people with disabilities become more isolated. In response, the care institution indicates that integration into society is not a realistic option for people with a mental handicap. They are safe in a sheltered environment, where they can have contact with fellow residents, it is said.

The realization of “support” or “co-citizenship” cannot take place from the traditional care frameworks. When this takes place, the realization can be done completely independently of the existing care organization and related structures. Support is a completely unique concept that makes a radical break with the past. Social integration can be achieved when social participation is also being worked on. Social participation, as it were, precedes social integration. Social integration is a state resulting from social participation. Virtually no attention is paid to social participation. Activities aimed at social participation do not take place from care institutions because their working method is not equipped for this.

Support requires a new organizational form, a different form than what is traditionally offered. Support is directed outward. Support is about being present in society and actually participating in it.

With mission statements and the realization of “small institutions” in residential areas, the disadvantaged situation of people with disabilities is only reinforced. Compared to other Western European countries, the Netherlands is still the country whose facilities for people with disabilities are still “institutionalised”. Failures that cannot fail to occur are then used to smooth the way back to

Chapter 5 (PR 4)

The role of a support professional

5.1 Introduction

The support professional work at individual level and is helping the person to help to shape his/ her directing role. The personality of the support professional plays an important role in this.

5.2 Personality and attitude of the support professional

Within the care sector, there are often contacts between the client and the support professional. The role of these employees is essential. The treatment and attitude aspects are important here.

The support professional is the supporter in all areas of life. So this can be supported at home, at work, in free time or whatever.

The support professional is required to adopt a certain basic attitude and behavior aimed at achieving the goals desired by the client.

Below are a number of elements

Living in society is the starting point of action	**Use normal colloquial language**
Respects everyone's origins and acts accordingly	Has specific means of communication to promote intelligibility and mutual communication
Endorses the importance of valuable and personal relationships	Uses normal manners
Supports people to shape their relationships and social contacts	Does not patronize
Supports people at home	Shows visible commitment to the person being supported
Promotes people's participation in the social, recreational, religious and cultural life of society	Has an eye for the individual
Actively enables people to make their own choices	Try to put themselves in the shoes and perceptions of others
Offers (visual) aids to clarify choices	Does not impose own norms and values

Has an eye (and an ear) for the choices people make	Does not immediately form an opinion about a certain behaviour of the person with a disability
Respects the choices people make, even if they go against their own norms and values	Try to understand behaviour by looking for backgrounds and reasons
Promotes that people feel comfortable	Ensures personal integrity
Provides services that meet people's wishes and needs	Respects and safeguards people's privacy
Sees every person as a person with unique possibilities	Brings people into contact with each other
Is aware of personal objectives	Offers manners
Uses methodologies tailored to the person to clarify objectives	Has a broad network/uses it professionally
Provides targeted support so that people can develop further and gain many experiences	Supports people to shape relationships and social contacts themselves
Supports people to develop further in the field of work / activities	Stimulates and supports people in contact with parents / family and friends
Respects everyone's origins and acts accordingly	Endorses the importance of valuable relationships
Respects everyone's lifestyle	Promotes a supportive network in the workplace

The support professional provides support to the client in accordance with the agreed care plan. The support to the client does not stand alone, but is placed in the context of the client's total life and expectations for the future.

In order to give substance and form to the desired starting points, an interaction between the support professional and the client will have to arise in the day-to-day support to the client.

5.3 Duties and responsibilities of support professional

The support professional supports the client in all areas of life.

The support professional is involved in determining the wishes of the client, recording agreements in the care plan and the plan of action.

In close cooperation with the client, the support professional manages the desired and agreed support that is offered and as laid down in the action plan. The support professional also plays a supporting role in the evaluation and possible adjustment of the care plan and action plan.

Furthermore, the support professional has a signalling function regarding the health and well-being of the client and calls in other, specific experts and expertise if necessary.

5.4 Competencies coach. Interfaces with the support professional

Some interfaces in the field of competence of the support professional are:

1. create trust: the client must feel safe;

2. listening: check whether what is stated is actually meant.

3. work methodically: the support professional will have to work methodically. He can use methods and techniques that are specifically available for support.

4. motivate.

5. stimulate.

6. promote self-management. The starting point is that the control lies with the client.

7. result-oriented work.

8. setting goals/drawing up an action plan.

9. evaluate.

People with a (mental) disability are dependent on permanent support and guidance. The support professional remains in the picture. This can often involve a long-term relationship with the (mentally) handicapped person. The support professional concerned will have to maintain his professionalism and leave room for the person with a (mental) disability to make choices.

5.5. The Role of a support professional

This chapter describes the role of the support professional. From a management point of view it is important to know what this role should be, what can be expected from the care professional, which competences are needed and how the care professional must be facilitated to able him/ her to fulfil the necessary role. It is also important that the support professional must be able to reflect and find out what the best practices are.

Chapter 6 (PR 5)

The attitude of the support professional

6.1 Introduction

There needs to be a paradigm shift in care. The thinking and acting of care employees based on supply-oriented activities must make way for an approach in which the client is central.

This is still a considerable problem within the care and services sector. The majority of care and services still take place within the so-called "development paradigm."

According to this paradigm, disabled people should be able to lead an existence as close to normal as possible. This development has led to deinstitutionalization.

However, little consideration was given to the wishes of people with disabilities. A comparison is made with the "normal" world, where the standard was the living environment and way of life of the "non-disabled person". From this "normalization", also referred to as "standard norm", care and service programs were fleshed out. The emphasis of the care and services was on the deviant, on the disability.

This is also referred to as "supply-oriented care". Persons with disabilities had to fit into this program offers. If this was not possible, it was examined whether there were more specialized programs or facilities that could accommodate the person with a disability. If the group of persons with the same characteristics had reached a certain size, it was examined whether a separate specialized facility could be set up for this.

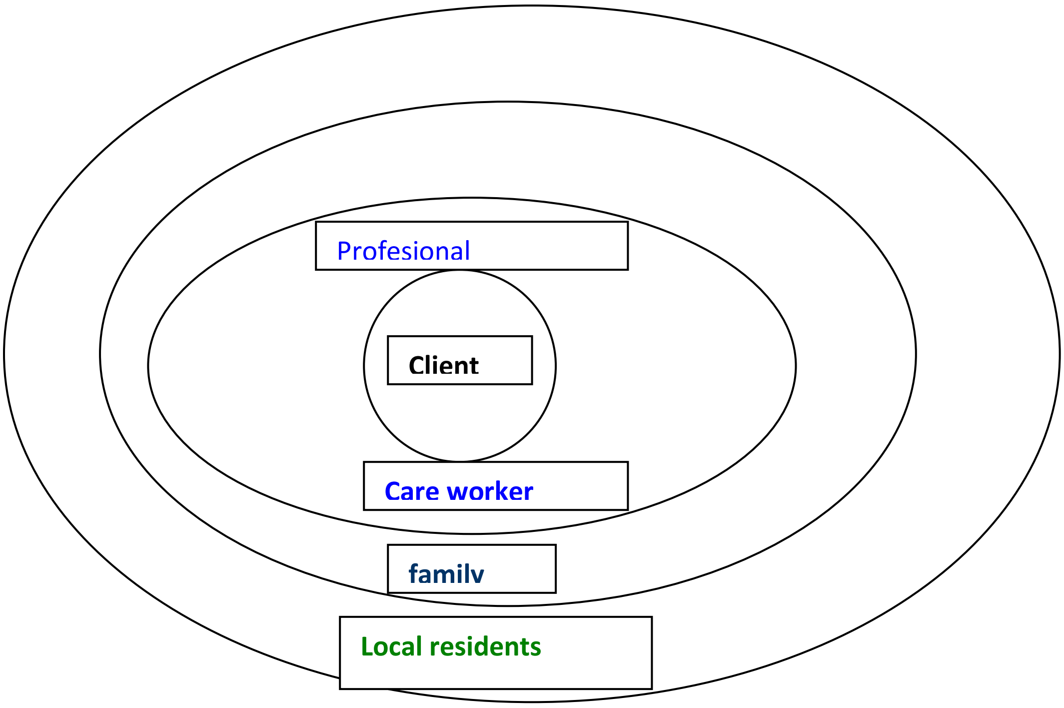
Examples of these developments in e.g., the Netherlands are the large number of types of special education and care facilities for specific groups. As indicated above, the focus was and still is largely on the handicap.

6.2 An example

Example 1

In the early 1990s, a visit to Sweden organized by the Ministry of Health, Welfare and Culture in collaboration with directors of Dutch care institutions. The ministry was of the opinion that the "Swedish model" should be followed in the Netherlands. The Swedish model involved small-scale facilities. The care was referred to as "community care." However, it were small scale facilities, which were present in society, where care and services were offered, they were completely isolated from society. In other words, it were small-scale institutionalized facilities (small institutions). This picture was confirmed by the intensity of the contacts between clients and care professionals. External contacts between clients and people from the immediate environment hardly took place.

From the previous example, the contact relationship can be schematically represented as follows:



The ministry has formulated the realization of small-scale facilities as a "decentralization policy." Large institutional grounds had to be dismantled and small-scale facilities had to be realized in residential areas.

Many care institutions have implemented this policy. The expectation of the policy makers was apparently that the presence of disabled people in a residential area would automatically lead to integration.

Example 2

A care institution has realized facilities for 75 clients in a number of homes. The houses are clustered. Furthermore, a central building has been realized for management, administration and day-to-day activities for clients. The facility has been in existence for more than ten years now. During that period, activities took place in isolation. Facilities that were needed were obtained from the central organization (the institute). Contacts with local residents mostly concerned complaints about noise nuisance caused by clients. The care organization has in no way looked at possibilities for participation in the immediate living environment. The practice has shown that this has not happened.

6.3 Paradigm shift

The paradigm shift that is necessary is characterized by the development of supply-oriented to demand-driven care.

The starting point for demand-oriented care is that the care recipient is in charge of the provision of care. An additional aspect relates to the fact that people with disabilities should be able to claim the same rights as people without disabilities.

Integration of people with disabilities must be achieved. In principle, people with disabilities should be able to be present in society and be able to participate in it. People with disabilities are fellow citizens. The shaping of co-citizenship should take place within the "citizenship paradigm".

The citizenship paradigm is based on the idea that a person with a disability can give form and content to his existence as an equal and fully-fledged citizen in society.

Schematically this can be represented as follows[20]

Development paradigm	**Citizenship paradigm**
The client	The citizen
A specialized facility	The person's home, the school nearby
Differentiated options	Care needs of each individual
Developing/behavioural	Individual support/support
Programs	Support
Individualized housing plan	Personal plan for the future
The interdisciplinary team	The individual person
Consistency within the team	Personal circles of support
Development of skills and behavioural aspects/control	Self-determination and relationships
Behavioral change	Change of environment and attitude
Documented programming and goal approach	The quality of life as experienced by the person in question
Aimed at society/community	Within society/community

6.4 The attitude

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[20] L. Boekhoff and M.Kamp. Supported Employment. The role of the care sector, pag 5 and 6. Publisher Stichting Zuidwester, 1994. ISBN 90 802207-2-B. L.Boekhoff en M.Kamp, Supported Employment. De rol van de zorgsector, pag 5 en 6. Uitgave Stichting Zuidwester, 1994. ISBV 90 802207-2-8

The support professional is expected to have an attitude that fits within this citizenship paradigm. This means, among other things, that the support professional should not indicate what is good for the client from his own point of view but should position himself in such a way that the client can determine for himself what he can and wants, and what is good for him.

The support professional will:

- must act in such a way that he can actually help the client in making choices.

- not be allowed to impose their own norms and values.

- must try to place themselves in the client's mind and experience

The support professional will have to have a certain basic attitude, basic behaviour, as indicated in the table below, already mentioned earlier.[21]

Living in society is the starting point of action	**Use normal colloquial language**
Respects everyone's origins and acts accordingly	Has specific means of communication to promote intelligibility and mutual communication
Endorses the importance of valuable and personal relationships	Uses normal manners
Supports people to shape their relationships and social contacts	Does not patronize
Supports people at home	Shows visible commitment to the person being supported
Promotes people's participation in the social, recreational, religious and cultural life of society	Has an eye for the individual
Actively enables people to make their own choices	Try to put themselves in the shoes and perceptions of others
Offers (visual) aids to clarify choices	Does not impose own norms and values
Has an eye (and an ear) for the choices people make	Does not immediately form an opinion about a certain behaviour of the person with a disability
Respects the choices people make, even if they go	Try to understand behaviour by looking for

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[21] Note for the design of the support core, Stichting Zuidwetsre, Middelharnis, September 29, 2003. Notitie ten behoeve van de vormgeving van de ondersteuningskern, Stichting Zuidwester, Middelharnis, 29 september 2003

against their own norms and values	backgrounds and reasons
Promotes that people feel comfortable	Ensures personal integrity
Provides services that meet people's wishes and needs	Respects and safeguards people's privacy
Sees every person as a person with unique possibilities	Brings people into contact with each other
Is aware of personal objectives	Offers manners
Uses methodologies tailored to the person to clarify objectives	Has a broad network/uses it professionally
Provides targeted support so that people can develop further and gain many experiences	Supports people to shape relationships and social contacts themselves
Supports people to develop further in the field of work/activities	Stimulates and supports people in contact with parents/family and friends
Respects everyone's origins and act accordingly	. Endorses the importance of valuable relationships
Respects everyone's lifestyle	Promotes a supportive network in the workplace

Chapter 7 (PR 6)

Description and practical examples of the presence and participation in the community of so-called "redundant" people using the accomplishments of John O'Brien

7.1 Introduction

Most people with a more severe disability do not yet participate actively in society. The possibility of participation is mentioned and even advocated in national government policy. However, institutionalization is still so great that radical transformations do not take place. The national government itself is largely to blame for this. At the end of the 1980s, a decision was made in favour of de-concentration in terms of the policy. People with a disability who lived on an institutional site started living in clusters in residential areas. However, the size of these clusters was such that small institutes started to emerge. The organizational form of the institute was continued in a smaller context. Furthermore, the facilities of the "old institute" were used. In other words, the orientation was and remained internally focused. During that period, policy documents referred to "community care". Care in society. What was missing, however, was the reciprocal aspect. On the one hand, the emphasis was on "care" : providing care, which is characterized by one-way traffic from the care provider to the care recipient, on the other hand, no attention was paid to the concept of "participation".

Nowadays, several people with a disability live in houses that are not distinct from the other houses. It is not correct to assume that this would also regulate participation. The fact that one lives/is present in a residential environment does not mean that there is also participation in what takes place in the residential environment.

With regard to the presence and participation of people with disabilities, a distinction is made between:

1. physical presence/participation;

2. functional participation;

3. social participation.

Physical presence/participation

This means that people with disabilities live in a house in an integrated living environment. They use the same homes that are also occupied by non-disabled people.

Functional participation

Functional participation concerns the use of the facilities available in the living environment. This may concern shopping facilities, cultural facilities, educational facilities, etc. The use of these facilities by people with disabilities is increasing. In cases in which the care institution continues to provide supplies, range of activities, etc. from the central organization, there is much less functional participation. In that situation, functional participation is also often limited to “walking” in the living environment.

Social participation

Social participation is about undertaking activities together with non-disabled people. Maintaining contacts, visiting each other, participating in club life, etc. Social integration is characterized by reciprocity. There is an interaction in the contacts between people with disabilities and non-disabled people. Initiatives emanate from both. There is no one-way traffic.

The social participation of people with a mental handicap is not doing well. Many people with disabilities have a limited network of contacts.

Most contacts concern family (especially parents), professional care assistants and co-residents within a care institution. The Social and Cultural Planning Office of the Netherlands has concluded that 'just participating' is not self-evident for children and young people with a physical or mental disability in society. Disabled people experience more obstacles in going to school, finding a job and in their leisure activities than other children and young people. Maintaining social contacts also often takes a lot of effort. Of the number of people with a mental disability between the ages of 18 and 29, 47% have no friends.

7.2 The Core Values of John O'Brien

It has already been indicated above that the aspect of “reciprocity” is of great importance in social integration.

John O'Brien has named five key values that should be met. These are:

1. be present in society.

This involves participating in ordinary life in society.

2. make your own choices.

This concerns the experience of autonomy both with regard to small daily things (such as what to eat) and in major aspects that are important for life.

3. have powers.

This involves the opportunity to function adequately and valuable activities with any kind of support and guidance.

4. be treated with respect and act respectfully.

This is about having a valuable place in a network of people and valuable roles in life in society.

5. participation in society.

This involves being part of a growing network of personal relationships, including friendships.

With O'Brien, it is all about the combination of the aforementioned points. It's about respect and giving space to others. Ensuring that the other person belongs and that he or she experiences it that way.

7.3 The presence theory of Baart

The theory of presence is about connecting with the people themselves. The presentation theory is all about the other. You open yourself up to the other person in every way. You join his pace of life. The role you fulfil depends on the other. Sometimes by just being there, sometimes by having a listening ear, and sometimes by paying attention to the little things. In the theory of presence, it is about meeting the other person in an open, unprejudiced way. In this meeting, space is created. For the other to just be and stay themselves. Space is also created, which is based on trust. This space that arises also offers opportunities for development, for personal growth.

For many people, it doesn't work out that much anymore. They are isolated, they are ignored, they no longer participate, they no longer belong. The theory of presence focuses on these people.

People with a more severe disability, who have little or no self-reliance, find themselves in similar circumstances. The organization of care around them has isolated them from society. They do not participate in this, they live in a closed care complex, they have no friends, and their circle of contacts is often limited to family members, professional care assistants and co-residents.

7.4 Participating in society

Participating in society means being present in it and functioning in an active way with non-disabled people.

The construction of homes in the residential area has regularly led to negative reactions from local residents. Prejudice plays a major role. In the past, people with a disability were placed in institutions outside their living environment, the starting point being partly to protect society against the 'handicapped'. Little experience has been gained with social integration. Good frames of reference and examples are still limited. Achieving social integration requires a great deal of effort from all parties involved. You see retreating movements from time to time in care. The argument is then given that disabled people are better off on the institutional grounds. There is safety in that area and they are not bothered by the living environment. It seems that the responsible managers of these care institutions are now going to use as an argument that "disabled people" must be protected from "society". An argument that has not been mentioned is that the care institution does not need to make any extra efforts and activities can be continued on the basis of the old familiar routines.

To make participation possible, connections must be made. The fact that there are few frames of reference means that this must be taken into account. We must look for that which can connect people, for that which is needed. In this way a meeting can take place.

Care institutions that are responsible for the organization and design of daytime activities for people with a disability can choose to convert the design of traditional daytime activities into outward-oriented activities.

Instead of organizing daytime activities in a closed daytime activity centre, the choice can be made for activities in a small shop. When looking for connection options, we look at the needs that exist in that shop. Care can contribute to this. When a store has disappeared, it can be considered to keep a store running with the help of clients. A specific need is met. A relationship is established with the population. Something can be expected from the population. Residents can also contribute by volunteering in the store. In this way a win-win situation is created. There will be opportunities for residents to get to know people with disabilities. This may result in further contacts and activation options. Professional care assistants are expected to play an active role here. They will have to draw up an integration program for each individual client, based on wishes and possibilities. Then you have to actively work on this. A passive setup will not lead to desired effects. This does not remove the isolation of people with disabilities. We need to build on strengthening social networks.

7.5. Individual options

Meeting opportunities can be created on an individual level. An example concerns a person with a severe disability. The person is dependent on a wheelchair, has problems with his motor skills and cannot express himself verbally. This person's world is small, both spatially and physically. Solutions could be found within the limitation. It turned out that this person has an interest in art. A professional artist has taken care of the person as an “art buddy”. In the beginning, the professional artist had to hold the hand of a person with a disability. Based on the muscle tension, it was then discovered which colours were or were not wanted. The professional artist completely tuned in to the other. A meeting came about. Trust arose. Over time, the person with a disability took control. A development process has taken place for both. The person with a disability has been able to develop further through art. The professional artist himself also learned a lot from this meeting because he opened up.

The father of this disabled person at a later date told that many of the works of art that was created were sold quite quickly. During the weekends, the person with a disability stayed at home with the parents. During the week he lived at the care institution. It was initially a problem for the parents to get him into the taxi on Monday morning to the care institution. Since he has been working on art with his “art buddy”, he wants to go back.

7.6 Conclusion

The overall aspect is being open and paying attention to the other person. It does not matter whether it concerns people with disabilities or people who are socially isolated for other reasons. The principles of John O'Brien and Baart fit well together. However, behaviour of care assistants that is characterized by routines will never contribute to giving social integration (presence and participation in society) a real chance. The attitude of care assistants will have to change.

Chapter 8 (PR 7)

Types of integration

8.1 Introduction

Integration is considered to belong to the conceptual framework that fits the “development paradigm". With integration, the responsibility for “adaptations” lay with socially disadvantaged groups, such as immigrants, the underprivileged, and people with disabilities.

With regard to the integration of persons with a disability, the following can be noted. A distinction can be made.

Physical integration

Physical integration concerns living here in a residential area. The neighbors are non-disabled people.

Functional integration

In functional integration, a subdivision can be made between passive functional integration and active functional integration.

The passive form of functional integration concerns the use of facilities available in society, including shops, medical facilities etc.

The active form of functional integration concerns participation in various segments of society, such as the labour market, education, and social life.

Social integration

Social integration mainly concerns contacts with people who do not belong to the institutional world.

Social integration of people with disabilities can only be achieved if social participation precedes it. In concrete terms, this means that targeted activities and support must be offered by the care organization in order to achieve this.

8.2 Inclusion

Inclusion means the inclusion of disadvantaged persons in society on the basis of equal rights and obligations.

Inclusion and integration complement each other in today’s society. In inclusion it is society that adapts and sees diversity in society as a condition.

Inclusion is considered to belong to the conceptual framework of the “citizenship paradigm”. The following applies:

- *the primacy of society*

- people with disabilities must be able to live in society

- all needs of every citizen are equally important

- needs are the starting point for the structure of society

- that all resources of society are used

- there are equal opportunities for participation.

- *with regard to the quality of life*

- the pursuit of a good quality of life for every citizen

- giving form and content to one's own existence

- according to general human and special basic needs

- under normal circumstances

- that one is satisfied with one's own existence.

- *with regard to choice and control*

- that people themselves choose how form and content are given to existence

a. with whom am I entering into a relationship

b. how shall I act

- that one has control over one's own existence.

- *with regard to support*

- support from others.

a. unconditional and flexible through social network

b. support by professional network.

An inclusive society welcomes diversity, respects differences and takes pride in the inclusion of all people. She stimulates lasting and friendly relationships between people. An inclusive society is a diverse society and offers opportunities for participation in and involvement with one's own environment. All facets of life, including culture, school, work, leisure time and faith, are seen as opportunities for meeting and further development.

8.3 Elements of Inclusion

Elements of inclusion are:

- process of valuing diversity within a community
- looking for positive aspects and talents
- emphasis on social emotional dimension
- the existence of people with disabilities becoming intertwined with the existence of others
- characteristic: Relationship and environment

- relations:

o interdependence

o connectedness

o equality

o support

o unity

o symmetry

o give and take

o belonging

o intimacy

o extra attention to

- emotional connection with significant others versus emotional ones loneliness
- opportunities for participation versus boredom and social isolation
- be part of a network of people who support each other being excluded

- fulfilling roles in life versus living with the role of the disabled person

- environment

- acceptance: recognizing the value of personal diversity

- activities: working in small groups on projects, collaboration.

  Stimulation and own role

- membership: support and solidarity

o takes place within a different understanding of intellectual disability

o no other word for integration

o task that needs to be worked on within society

o living, working and recreating in society is necessary, but not enough

Specific

o beyond integration, no “community care”, but active in society

o Inclusion is important as part of a good quality of life

- personal meaning is important, so for people with an intellectual disability that attribute meaning to it.

- significance of social networks

o building, expanding, maintaining social networks

o give all persons the opportunity to participate in the society to live.

o sufficient financial preconditions (small groups, individual accompaniment)

o consider whether de-institutionalization is better than institutionalization .

8.4 Initiatives from society

As indicated above, inclusion is about adapting society. In the field of inclusion for people with disabilities, a Coalition for Inclusion has been established in the Netherlands.

The Coalition for Inclusion aims to:

- Bringing an inclusive society closer by creating positive connections between people, organisations, initiatives, governments and others who are committed to inclusion.

- Offering support and inspiring and strengthening people who want to realize an inclusive society.

- Getting inclusion as a continuous point of attention on the local, national (and European) policy agenda, so that an inclusive society takes shape.

- Stimulating inclusive thinking by promoting innovation and differentiation and investing in experiential knowledge and research. Partly aimed at a positive attitude of society to welcome people.

Objectives Living in society

- People live with and with others with whom they feel connected, in the middle of society, being part of their own social network.

- People live in a place of their own choice, where they feel at home.

- The legal right to independent living of people with disabilities is regulated. The right to own a home is recognised, a sufficiently high income to realize participation is made possible and the living environment is made materially and immaterially accessible.

- People have meaningful relationships to establish and develop at work, in the neighbourhood, in the immediate vicinity.

- There are enough available people and organizations that can offer support in participating in society in a way that suits him/her. Or who can support coordinating services to them.

Objectives Working in Society

Working on showing good examples and breaking down the barriers surrounding working in society.

Objectives are:

- People carry out valued activities or activities in society that match their ambitions, interests and possibilities.

- People develop further in their work, gain experience and knowledge.

- People receive a lifelong personal participation budget, which can be used to pay for guidance and support in the workplace.

- Accessibility of public transport is quickly arranged.

- Young people with a disability are supported in making plans about and organizing their adult lives.

- People, organizations and companies work together towards an open society where everyone's contribution is respected and rewarded.

- People and organizations that support people in their participation in society or that can coordinate services to them are available.

Objectives Learning in Society

- People follow widely accessible, regular education.

- People train themselves in areas where their interests and ambitions lie.

- Regular education is open to all children. Adult education, all kinds of vocational education, courses, etc. are also open to everyone.

- The right to education for all children is laid down in law.

- It is established which forms of support are effective at school and who is responsible for organizing this.

- Applied scientific research to support schools is carried out, teachers are trained on inclusion.

Inclusion in Relation to Work

The great example of inclusion in the field of work concerns Supported Employment. Supported Employment is understood to mean: supporting people with disabilities in obtaining and retaining work at a regular workplace. The support and guidance is individually focused.

Inclusion with regard to daytime activities

For a large number of people with disabilities, a paid job on the regular labour market is not a realistic option. Examples of realised initiatives are local shops run by people with disabilities and volunteers.

Inclusion in relation to housing

Persons with disabilities can live independently in an ordinary house in an ordinary neighbourhood with the help of individually targeted support. The support offered can be financed from a Personal Budget (PGB) or from care in kind. In the latter case, the care is provided by a care provider.

Inclusion in Relation to Leisure

Many people with (intellectual) disabilities are isolated and have no friends. An initiative to break through this is the Best Buddies Program that was introduced.

The Best Buddies Program is a friendship program in which a person with an (intellectual) disability and a non-disabled person, for at least one year:

- develop a joint activity every two weeks

- have weekly contact.

The person with an (intellectual) disability is offered the opportunity to make new contacts and to participate in networks outside the circle of the disability sector.

Inclusion in relation to education

An example of this is the so-called "Backpack", which can be used. A pupil with a disability can participate in general regular education. Extra guidance is given additionally from the money that is available in the "Backpack".

8.5 Final Note

Adapting society towards inclusion is still a long way to go. The interactions between disabled and non-disabled people in a residential area are still very limited.

If inclusion is to succeed, active efforts will have to be made to promote the social participation of, among others, people with disabilities in society. The aspect of reciprocity should be explicitly included in this. This should respond to the needs of society. An example is the core policy that focuses on preserving and strengthening the quality of life in small centres. People with disabilities can contribute to this through daytime activities. Responses from the environment can be generated, creating win-win situations. People with a disability meet people without a disability, contribute to society and are positively valued.

Chapter 9 (PR 8)

The relationship between the Human Rights Convention and the essential elements of support

This chapter examines the role relationship between the United Nations Declaration of Human Rights and the essential elements of support.

9.1 Introduction

The Preamble to the United Nations Universal Declaration of Human Rights states that recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.

It is further stated, among other things, that it is of the most importance that human rights be protected by the supremacy of law, lest man be compelled to resort as a last resort to rebellion against tyranny and oppression. The Charter reaffirms faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women.

The Universal Declaration of Human Rights is not legally enforceable, but can be seen as an intention for countries to act accordingly.

From a historical perspective, the Universal Declaration represented a major step forward. In individual treaties, for example, countries have turned against genocide. An International Court in The Hague has been appointed to try such offences. This is about excesses. Many steps still need to be taken to create an international society where the rights of individuals are respected.

9.2 The Human Rights Convention aimed at people with disabilities

The Convention aimed at people with disabilities is based on general human rights, but pays specific attention to the position of people with disabilities. The Convention can be seen as international law, which comes into force when it is ratified by countries. With ratification, these countries undertake to comply with the provisions of the Convention. The United Nations will regularly issue a report on the state of affairs. In this way, the report forms a means of pressure for the authorities involved.

The general principles of the Convention are:

The respect for the inherent dignity, individual autonomy including the freedom to make one's own choices, and the independence of persons;

Non-discrimination;

Full and effective participation and integration in society;

Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity;

Equal opportunities;

Accessibility;

Equality between men and women;

Respect for the developing capacities of children with disabilities and respect for the right of children with disabilities to preserve their identity.

9.3 Are rights sufficient for people with (intellectual) disabilities to enjoy full inclusion?[22]

Parmenter concluded that just rights are not sufficient and referred to:

1. Low participation in the labour force, 30% of people with intellectual disabilities.
2. 12% of people with an intellectual disability were employed full time.

In a comprehensive review of literature, Verdonkschot et all (2009)[23] was found the following:

a. the average number of persons in their social network was 3.1, one of which was a paid support worker;
b. they are 3-4 times less employed than non-disabled persons.
c. they were less likely to be employed competitively and were more likely to work in sheltered workshops or segregated settings than those with other disabilities.
d. they were less likely to be involved in community groups.
e. leisure activities were mostly solitary and passive in nature.
f. they were generally accompanied to an activity by support staff.

Parmenter underlined the need to find an alternative approach which may help achieve full inclusion of people with intellectual disabilities. Further he concluded that it is imperative for the achievement of dull inclusion of people with intellectual disabilities that there is an engagement with the wider community.

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[22] Paper from prof. T. Parmenter, Sydney Medical School, University of Sydneay, Australia, Springer, Published on lie 3-08-2023. https//doi.org/10.1007/541252-023-00351-4

[23] Verdonkschot,M.M.L., de Witte,L.P., Reinchraft, E., Buntinx,W.H.E., Curgds,L.M.G. (2009). Community participation of people with an intellectual disability, Journal of Intellectual Disability Research 56 (11), 303-318. https://doi.org/10.1111/j.1365-2788.2008.01144.x

9.4 Elements of Support

The essential feature of support is to focus on the person with a disability as a fellow citizen with the same rights and obligations as non-disabled people. The person with a disability must be able to assert these rights. Because of his disability, he needs support and guidance. No more than necessary and no less than necessary. Support is based on a new perspective, also known as the “citizenship paradigm”.

Below are some concepts that belong to this paradigm

Period of citizenship
The citizen
The person's home, the company where they work, the nearby school that they attend
Care needs of each individual
Individual support (support)
Support
The individual person
Personal circles of support
Self-determination and relationships
Change of environment and attitude
The quality of life as experienced by the person in question
Within the community/society

The person with a disability gives shape and content to his life. This citizenship paradigm not only expects a lot from the person with a disability, but also from the environment. What is new about this view is that a disability is no longer seen as a property of the individual, but is an expression of the interaction between the individual and the environment.

The support also focuses on the role that the environment can play in reducing the disability(s). There is a social challenge here.

The emphasis is on the principle of equality: people with disabilities have the same social needs as others, equal rights and they should be given equal opportunities: The aim is to achieve real integration. This involves living in a residential area, making use of the same services and facilities as non-disabled people. The person with a disability participates in society and receives the necessary support.

9.4 The Implementation

Paper is patient. The declarations issued by the United Nations, which have been signed and ratified by various countries, do not automatically lead to the implementation of equal opportunities and opportunities.

Healthcare institutions use “mission statements” in which the principles of support are leading. The implementation practice is often different and not congruent with the mission of the organization.

Both the declaration of the United Nations and the mission of a care organization should also include an implementation program. A country that signs and ratifies the declaration should link it to a policy that does justice to the general principles. A care institution that has a support mission must base its care and services on this.

Chapter 10 (PR 9)

Paradigm shift (development from institutionalisation, de-institutionalisation to support)

10.1 Introduction

The development in care for person with a disability is characterized by three phases, which are showed in the following table.

THREE PHASES IN THE DEVELOPMENT OF SERVICES FOR PEOPLE WITH DISABILITIES

	Phase 1	**Phase 2**	**Phase 3**
Focal question	Institutional reform period	Deinstitutionalisation period	Community membership period
Who is the person of concern?	The patient	The client	The Citizen
What are the “typical" service settings?	An institution	A group home, a sheltered workshop, a special school or classroom	The person’s home, a local business, the neighbourhood school
How are services organised?	A facility	A continuum of options	The unique array needed by each individual
What is the “model” of service delivery?	Custodial/Medical	Developmental/ Behavioural	Individual Support
What are services called?	Care	Programs	Support
What is the planning model used?	Individual Plan of Care	Individualized Habitation Plan	Personal Future Plan
Who controls the planning process?	A professional (often an MD)	The interdisciplinary team	The individual
What is the context of decision-making?	Standards of professional practice	Team consensus	Personal circles of support
What receives the highest priority?	Cleanliness, health & safety	Skill development & behaviour management	Self-determination & relationships
What are the major focuses of intervention?	Control or cure the condition	Change behaviour	Change the environment and attitudes
What is the focus of quality assurance standards?	Professional practise & minimal standards of care	Documented programming & goal attainment	Quality of life as experienced by the person affected
How do providers talk about their services?	Community Outreach	Community-based	The community

Boekhoff,L, Kamp,M. Supported Employment en de rol van de zorgsector, pag 5 en 6. Stichting Zuidwester, November 1994. ISBV 90-802207-1-X.

10.2. Institutional reform period

The period of institutionalisation, phase 1 is also referred to as the stage of the defect-paradigm. The defect-paradigm means that the individual human being with his limitations is first and foremost a patient in need of care. Men is seen as a biological object; an organism that may or may not have defects that can be remedied. If such a limitation means that someone can no longer meet the accepted norms and values of society there is a disability. Persons with a disability are admitted to institutions that were removed from civilization. Isolation from society was considered necessary not only to provide them with proper care, but also to protect society against them. Goffman[24] , American researcher, characterizes working with people in institutions as "material to work with". Human can take on the same characteristics as soulless objects.

10.3. Period of de-institutionalisation

The period of de-institutionalisation, phase 2, also referred to as the development paradigm. According to this paradigm, disabled people should be able to lead an existence as close as possible to normal. They are no longer seen as participants, but as ordinary people with specific needs and with their own development potential. The development in this phase has led to de-institutionalisation. Little consideration was given to the wishes of people with disabilities. The basis of this thinking was in the categorization of people in need of care and "normal" people. Also referred to as "normalization". The normalization then comes down letting the disabled live in an environment according to the norms of the "standard man". For example, in the Netherlands this has led to an increase in specialized facilities and schools in terms of care and services. The emphasis was on offering programs to which persons with a disability were subjected and to fit in. The disability was the focus here and not the person himself/ herself.

10.4. Period of citizenship

The period of citizenship, phase 3, also referred as the citizen paradigm. The citizen paradigm is based on the idea that a person with a disability can give form and substance to this existence, as an equal and fully-fledged citizen in society. He does, however, need support and guidance because of his limitations. The emphasis is on the principle of equality. People with disabilities have the same social needs as others. They have equal rights and should be given equal opportunities. The possibilities of the persons are considered instead of the impossibilities due to the disability. The rights that a person with a disability has must also be able to be enforced"

This shift has also initiated a development with regard to the quality of care and services for persons with disabilities and to the quality of life. The support and guidance to persons with a disability is referred to as "support".

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[24] Goffman, E. The prison. Dutch translation. Total Institutes, pag 63. Publisher University Press Amsterdam, 1975. Goffman,E. The prison. Totale instituties, pag 63. Uitgeverij Universitaire Pers Amsterdam, 1975. ISBN 90237 11688 NUGT 652

Chapter 11. (PR 10)

Elements of de-institutionalisation compared with elements of support

11. 1 Introduction

The general intention of de-institutionalisation is to create opportunities for inclusion of person with a disability.

Large care organisations have realised small scale housing for people with disabilities. Life and support are often largely determined by professionals and services. Often there is no free choice with whom one lives together. The person's control over the support is limited because the care professional do not work for the individual but for the whole group.

This means that the institutional characteristics are dominant. In practice in many situations it is an institute on a smaller scale.

A person with a disability can live an institutionalised life in the living situation if the facilities, services and possibly even the regulations prevent them from fully participation and living with the same freedom and choice and fullness that person's without disabilities can take for granted.

Complete de-institutionalisation is seen as a process by which persons with a disability regain or retain opportunities to live an independent life in society.

11.2 Obstacles

In the process of complete de-institutionalisation one can be confronted with a number of barriers, these can include:[25]

- Policies and regulations do not sufficiently support personal autonomy or even ensure that there are few personal autonomy opportunities;
- Lack of options for a suitable home in society;
- Lack of options for support to function in society;
- Lack og encouragement, empowerment opportunities and support to develop personal skills;
- Survival of powerful large-scale collective institutions and supply-driven services
- Persistently caring attitudes and low expectations towards persons with disabilities are still prevalent ikn society, in many families, among professionals and policymakers;

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[25] GRIP: To a life of their own in the middle of society. gripvzw.be. GRIP. Naar een eigen leven midden in de samenleving. gripvzw.be

- Socio-economic factors limit the ability to exercise freedom of choices and control over one's own life, which also results in a disadvantageous position on the labour market and a weak income position;
- Social isolation due to, among other things, a lack of appropriate support and measures to integrate people into the community, even if they live in a house in the community. Continued stigma, hostility and negative attitudes further foster social isolation and can lead to discrimination.
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11.3 Community care[26]

Community care is defined as the provision of services and support to the elderly, ex-psychiatric patients, people with a sensory physical or mental disability who need this support to live as independently as possible in their own homes or in housing in the community.

Community care is related to a number of related concepts, such as de-institutionalisation. This is understood to mean the process whereby institutions are replaced by small-scale forms of housing and homes in society.

The purpose of community care is denied as: supporting people with severe disabilities (including support for their social network) in living and participation in (local) society. Important domains are here family life, education, work, housing and living environment, mobility options, friends, recreation, leisure time and health.

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[26] Community care: The challenge for the Netherlands. Drs. Esther Plemper, Dr Katja van Vliet, January 2003. From RMO Advice 23. The handicap of the society., November 2002. Community care: de uitdaging voor Nederland. Drs Esther Plemper, Dr. Katja van Vliet. January 2003. Uit: RMO Advies 23 De handicap van de samenleving, november 2002

The objectives are included in the table below[27]

Name	Description	Objective	Methods	Responsibilities
Support participation of people with disabilities in society	Support participation of people with disabilities in society from society itself	Participation of people with disabilities in society	Support for social networks and organisations such as housing associations, companies, schools, community centres, sports facilities and public transport. Making offering accessible to people with disabilities with regulatory facilities, including necessary funding-instruments	Care organisations. Regular organisations for education, housing, work, care, sport, transport. Local governments. Society

In practise often the following situation occurs.[28]

Practise	Objective	Method	Responsibility
Care by institutions on society	Supporting people with (severe) disabilities in living in a home of the care institution	Support is provided by a care organisation, in work or day time activities, at school, in leisure activities. People with a disability are given a little more influence over their own life. Society not been made actively co-responsible for caring and supporting people with (severe) disabilities	Care organisations

Real community care includes a responsibility of citizens in society.

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[27] Community care: The challenge for the Netherlands, pag. 26. Drs. Esther Plemper, Dr Katja van Vliet, January 2003. From RMO Advice 23. The handicap of the society., November 2002. Community care: de uitdaging voor Nederland, pag. 26. Drs Esther Plemper, Dr. Katja van Vliet. January 2003. Uit: RMO Advies 23 De handicap van de samenleving, november 2002

[28] Community care: The challenge for the Netherlands, pag 27.Drs. Esther Plemper, Dr Katja van Vliet, January 2003. From RMO Advice 23. The handicap of the society., November 2002. Community care: de uitdaging voor Nederland, pag. 27. Drs Esther Plemper, Dr. Katja van Vliet. January 2003. Uit: RMO Advies 23 De handicap van de samenleving, november 2002

11.4 Barriers to community includes e.g.

- Long tradition of care provided by institutions

- Quality of buildings: capital destruction

- Actors entangled in care system

- Inward looking and closed care institutions

- Few connections between care and the social sector

- Traditional education and attitude of care p;rofessionals

11.5 Citizen paradigm

The citizen paradigm is strongly linked to support and is in line with the objectives of community care.

Domains of life of community care are[29]

Domains	Conditions
Living and living environment	Regular living with or without adaptation. Own choice for residents. Facilities in surroundings. Adapted social living as security is at issue
Earn income	In principle through regular work with or without support. (Supplementary benefit)
Training and knowledge acquisition	In principle regular education and training with or without support
Work	In principle regular work with or without support
Daytime activity	In principle in the society in integrated

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[29] 29 Community care: The challenge for the Netherlands., pag. 48 Drs. Esther Plemper, Dr Katja van Vliet, January 2003. From RMO Advice 23. The handicap of the society., November 2002. Community care: de uitdaging voor Nederland, pag. 48. Drs Esther Plemper, Dr. Katja van Vliet. January 2003. Uit: RMO Advies 23 De handicap van de samenleving, november 2002

	settings with or without support
Social contacts	Form and maintain social contacts: through network analysis
Self and family care	Care on call. Support from own network. Agreement between professional and volunteers and informal carers
Transport	Regular public transport with or without support/guidance

To gain full citizenship of persons with a disability it is essential that they are included and are able to participate in society.

Chapter 12 (PR 11)

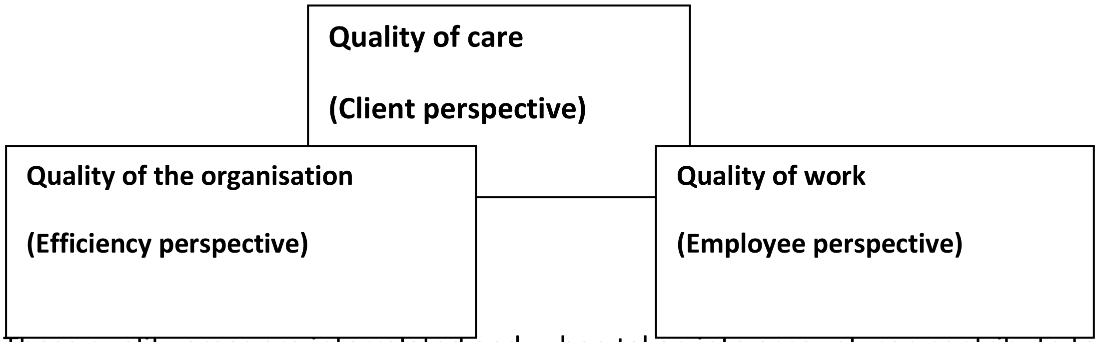
Description of organisations structure, competences and management styles

12.1 Introduction

Care organisations that want to give shape and substance to support-driven care from the perspective of persons with a disability must not only ensure that the mission, goals and strategy of the organisation are aligned with this, but also that the organisation itself is brought into line with this.

12.2 Changes in the care sector

Boonstra et all (2007, 1771) argue that in change processes in the care sector, the aim should be to jointly optimize three quality areas, namely: quality of care (client perspective), quality of the organisation (efficiency perspective) and quality of work (employee perspective).



These quality areas are interrelated and, when taken into account, can contribute to a positive development of the intended care and services for persons with a disabilit

Far reaching changes, such s from supply-oriented to demand-oriented support care have consequences for the organisational structure, culture and management style, among other things a shown in the table below.

Typology of a supply-oriented, demand- oriented and demand- driven organisation

	Supply-oriented organization	***Demand-oriented organisation***	***Demand-driven organisation***
Structure	Bureaucratic	Team-based	Individually

	Centralistic Mono-disciplinary Separate services	Multidisciplinary Locations Integral management	targeted Independent units Decentralized organization Facilitative management
Culture	Roles/ functions Internally focused Top down Problem voiding	Tasks Team spirit Top down/ bottom up Problem solving	Person-oriented Innovative Bottum up Problem preventing
Management style	Directive	Participating/ coaching	Coaching/ participating
Administration	Standardization Top down Budget management	Location based budget management Budget per team	Personal of person-following budget
Typology	Professional bureaucracy	Division structure	Adhocracy/ service

G. Verbeek, Artema, Bilthoven 2002

Characteristics of a demand-driven support organisation are a flat organisational structure (independent units), responsibilities as los as possible in the organisation and supporting and facilitating role for managers.

12.3 Competences

A competence is the ability of an individual employee to perform a task in practise under different circumstances and that should lead to the realisation of desired outcomes (according to Brenner et all, quoted in Vraaggestuurde zorg: Van trend naar praktijk, Sebregts, Ellen, Erasmus Universiteit Rotterdam, 2007, 22).

Akkerboom et all (2005, 23) add that this must involve successful behaviour. This concerns behaviour within the context of the organisation or position that is expected of a person.

Essential competences for employees to be able to work demand-drive.

Akkerboom et all (2005, 23) distinguish three component, namely knowledge, skills and characteristics. Characteristics are of a personal nature and can hardly be changed, but they have a major influence on behaviour without this being directly observable.

The context of the demand-driven support care implies different competences than in a supply-oriented organisation. The focus on competences is directed from the inside out, decentralised, enterprising and dynamic.

Akkerboom et all (2005, 33) named the seven competences that employees need to be able to work in a demand-driven support organisation. These are shown in the table below.

Essential competences for employees

Conceptual	**Operational**	**Relational**	**Personal**
Solution orientation	Anticipating Organisation ability	Client orientation Negotiate	Flexibility Independence

Akkerboom et all 2005

12.4 Role management

Adjustments from a supply-oriented organisation to a demand-driven support organisation are drastic changes for the organisation. Management plays an important role in this and opts for a change strategy that, through interventions leads to as little resistance as possible.

Cozijnze and Vrakking (2003,189) state that when implementing changes, it must be ensured that those involved do not revert to "old behaviour". This involved must be taught to deal with changes, to maintain them and to adjust them when necessary.

The chosen strategy must be based on the implementation of wishes to change. (Cozijnse en Vrakking, 2003, 185-186). The management must translate the wishes into a change document that clearly describes what the "soll situation" exactly entails. The manager is expected to adopt a consistent attitude and that is "packed through" to achieve desired results.

A slow execution should be avoided. After the decision to change has been made, implementation should start as soon as possible, otherwise there is a riks that opponents will slow down the process and let the process crumble. Necessary actions must be carefully planned in advance, they must be irreversible. This can prevent that there is room to lower the target level.

For the implementation of the changes, there must be a clear work schedule for both preparation and implementation, with a time phasing. A great deal of attention must also be paid to information transfer. As preconditions for the implementation plan can be mentioned.

- Commitment and actual efforts from management
- Creating support among employees
- Continuity in the change process
- Phasing in time, with clearly indicated steps
- Timely evaluation and assurance of the processes
- Facilitating responsibilities
- Provide training and education to those involved
- Provide coaching (can be both group and individual coaching)
- Information and knowledge transfer to the organisation
- Establishing (new) job profiles
- Determining the required competences
- Establishing decentralised work units
- Appointing employees to new positions.

12.5 Person centred approach

" A person-centred approach is recognized as a foundation for achieving safe, high-quality health care, contributing to better outcomes and experiences for patients, carers and families."[30]

NOUS underlined the importance of achieving persons-centred care by all organisations rather than focusing on high-profile, well-known examples of persons-centred care.

They identified seven attributes of person-centred health care organisations, which are:

"Comprehensive care delivery

This is based on person-centred values applied in every interaction with patients, their carers and families. Effective communication drives care and compassion; patients are actively involved in their care involved in their care and decision-making is shared. Care is comprehensively coordinated across the team and guided by patients' goals and choices, while diversity and equity are respected and supported.

A clear purpose, strategy and strong leadership

Leadership drives the organisation to achieve exceptional person-centred care. Organisational commitment toward this goal is clearly stated in the organisations' purpose and articulated to the workforce and the community. Leaders at every level champion the importance of person-centred care across the organisation.

People, capability and a person-centred culture

These are focused on supporting the needs and choices of the individual. A long-term, systematic commitment to developing a person-centred culture is complemented by comprehensive training and capability development. Workforce wellbeing is prioritised and supported as a key enabler of great care.

Person-centred governance system

Such systems involve consumers at all levels of the organisation. Consumer involvement is enabled by thorough training and support. Co-design and co-production are frequently used to enable meaningful consumer involvement and service improvement. There are clear

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[30] Australian Commision on Safety and Quality in Health Care, pag. 4. Review of key attributes of high-performing person-centred health care organisations, NOUS group, 2018. www.safetyandquality.gov.ay

accountabilities for individuals and teams at every level of the organisation. Management decisions, including resource allocation, explicitly consider and prioritise persons-centredness.

Strong external partnerships

Strong partnerships are recognised as integral to coordinating services around the needs and preferences of individuals. Seamless transitions between care settings are enabled, with the organisation taking a leadership role in effecting system change and improvement.

Person-centred technology and built environments

These having a significant practical impact on experiences of care. While resources for both are often limited, good physical design principles and innovative digital technology are able to be applied in any organisational setting. Technology is used as an enabler for person-centredness and not a replacement for people, culture and capability.

Measurement for improvement

Achieving persons-centredness requires an organisation-wide culture of continuous improvement, focused on measuring patient outcomes and experiences. High performers "measure what matters" to get the outcomes that patients expect.

Chapter 13 (PR 12)

Structure and Culture of supply-oriented care versus demand-oriented support care

13.1 Introduction

The developments in care from supply-oriented care to demand-driven support care has impact on the relationship between the care provider and the care receiver.

This new relation means:

1. An equal interaction between care recipient and care provider.
2. An interaction in which the care recipient indicates what offer he want/ needs and a care provider who listens, informs, advises and who encourages the care recipient to indicate what he needs.
3. The demand of the care recipient leads to a suitable offer for him.

13.2 Demand-driven support care

The change to a demand-driven support care has impact on the structure and culture of the care provision.

Sebregts (2007, 20 and 231) has identified pairs of concepts that best fit supply-driven care and demand-driven support care. These are “structure” and “culture”.

Demand driven care and services for people with disabilities

	Supply-driven care	*Demand-driven support care*
Structure	Function oriented From the outside in Centralization Control Structuring	Competence oriented Inside out Decentralisation Enterprising Dynamizing
Culture	Process-oriented Work-oriented Organizational Normative Certainty Formal Control Homogenization Stability Inequality Closed Tight control	Result-oriented People-oriented Professional Pragmatic Uncertainty Informal Flexibility Individualization Change Equality Open Loose control

Sebregts (2007) [31]

It means that the structure of the services and the culture need to be in line with the type of care provision.

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[31] Vraaggestuurde zorg: van trend naar Praktijk. Een explorerend onderzoek naar factoren die in het veranderingsproces van aanbodsturing naar vraagsturing een rol spelen. Erasmus Universiteit Rotterdam, Ellen Sebregts, Rotterdam, september 2007. https://thesis.eur.nl/pub/4482sebrgtsE.pdf. Research to factors who play a role in the change from supply driven care to demand driven care. Eras mus University Rotterdam, Ellen Sebregts, Rotterdam, sept 2007

Chapter 14 (PR 13)

Differences between quality of care and quality of life

14.1 Introduction

In the citizen paradigm, the focus shifts from quality of care, which mainly focuses on the care products offered by the care provider, to quality of life.

The differences describes by De Wael et all (cited in the article Quality of Life, Arduin, December 2007) are as follows:

Focus	***Quality of Care***	***Quality of Life***
Perspective	The care provider, the organisation, the professional	The person himself in his natural network
Importance	Organizational processes must run smoothly: large overheads as a result	Desired results for the individual person: lithe overhead
Content	Management of care systems: leads to large scale and group thinking	Individual support and its effects on one's personal life
Typical criteria for assessment	Efficiency, cost effectiveness, planning, user satisfaction	Value based long-term outcomes of inclusion, personal fulfilment and self-determination
Structures	The current care systems just need to be improved, tight hierarchy	Support should help someone personally, even if it means finding alternative structures. Little hierarchy in the organization, self-management and coaching

De Waell et all: December 2007

14.2 Quality of life

Quality of life, according to Van Loon, are perceptions, behaviours and conditions associated with quality of life that give an indication of a person’s well-being. The context for the individual support is society. It is important that people with disabilities can participate in society. Care organisations play the role of supported and road preparer.

Social inclusion (social integration and participation) must precede social participation. In concrete terms, this means an outward looking and purposeful action of the care support worker. This requires an active approach. This includes individually oriented planning, in which the person with a disability has a central role. The support should be based on what has been agreed in the individual plan. The plan and support should also be evaluated.

Care organisations are tasked with providing care and services to individuals with disabilities in the areas of living, work/ daytime activities and leisure time. This should be done in a way that contributes to the promotion of the quality of life of the care recipients.

Quality of life involves both subjective and objective indicators. According to Van Loon, the quality of life is influenced by personal and environmental factors and the interaction between them.

Starting point for measuring or evaluating quality of life are:

- The quality of life of people with disabilities is about the same as what is important for everyone.
- Quality of life is increased if people themselves participate in decisions regarding their own lives.
- Quality of life is increased by accepting and fully integrating people into their own local society.

14.3 Quality of life domains of Schalock and Verdugo[32]

Domains of quality of life are all factors that collectively form personal well-being. Schalock and Verdugo distinguish the following eight domains:

- Emotional well-being: concerns, for example, being taken for granted, being treated with respect, safety and security.
- Interpersonal relationships: being able to maintain one's own social network.
- Material well-being: concerns the material condition that preserve human dignity, such as privacy, your own space where you can receive visitors.
- Personal development: getting opportunities for personal growth, opportunities to learn and experience.
- Physical well-being: being taken seriously in your physical integrity.
- Self-determination: derive self-respect from the fact that you are allowed to make your own choices; make decisions yourself.
- Social inclusion: being present in society and participating in it, belonging.
- Rights: experience that your rights are due.

The domains of Schalock and Verdugo form the basis for measuring the quality of life of people with disabilities. A context and a reference line have been indicated on the basis of which testing can take place.

Schalock et all set requirements for the care organisation. The organisation should be a learning organisation, having a culture or system of values that encourages learning and enables ;processes to integrate new information and enable change. As a characteristic of a learning organisation, it is indicated that there must be innovation, research orientation and goal setting.

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[32] Schalock, R.L & Verdugo, M.A, Handbook Quality of life for human service practioners . Washinton DC. American Association on Mental Retardation, 2002

14.4 Working on quality of life in organisations

According to Schalock et all, the following is important for embedding working on quality of life:

- Client involvement, including: in the development of their individual support plan; decide for themselves what is important to them.
- Education on important values: inclusion, self-determination, personal development.
- Individual support: person centred; based on dialogue; flexible; pro-active; based on measuring support needs and measuring support outcomes.

The processes that are important with regard to quality improvement in an organisation are:

- Leadership: work towards a shared vision, encourage training, feedback, promote inclusion, and emphasize the importance of measuring support outcomes.
- Learning teams: self-managing teams, focused on the challenge of new goals, focused on knowledge acquisition.
- Evidence-based working, which means: using support outcomes in organisational change and improvement; thinking from right to left. The focus should be on outcomes/ results of support rather than input; on goals rather than rules.
- Self-evaluation: as a basis for organisational change/ improvement.

In further research, Schalock, Gardner and Breadly have shown that three main indicators can be distinguished among the domains mentioned:

- Independence: personal development; self-determination.
- Social participation: interpersonal relationships; social inclusion; rights.
- Well-being: emotional well-being; physical well-being; material well-being

Schematically this is shown as follows

Quality of life factor	**Domain**	**Indicators**
Independence	Personal development	Education, personal competence, skills
	Self-determination	Autonomy, personal control, personal goals and values, choices
Social participation	Interpersonal relationships	Interactions, relations/ friendships and support (emotional, physical,

	Social inclusion Rights	feedback) Integration and participation in society, roles in society, social support/ supports Human rights (respect, dignity, equality) and legal rights (citizenship, access, fair treatment)
Well-being	Emotional well-being Physical well-being Material well-being	Satisfaction, self-image, freedom from stress Health, daily life activities and leisure Financial status, work and shelter

14.5 Influence of the domains of Schalock en Verdugo

The interpretation of the domains related to quality of life by Schalock and Verdugo has has a major impact on the way in which care services should be designed.

The emphasis has shifted from quality of care, with a particular focus on the care products offered by the care provider, to individual support for the person with a disability.

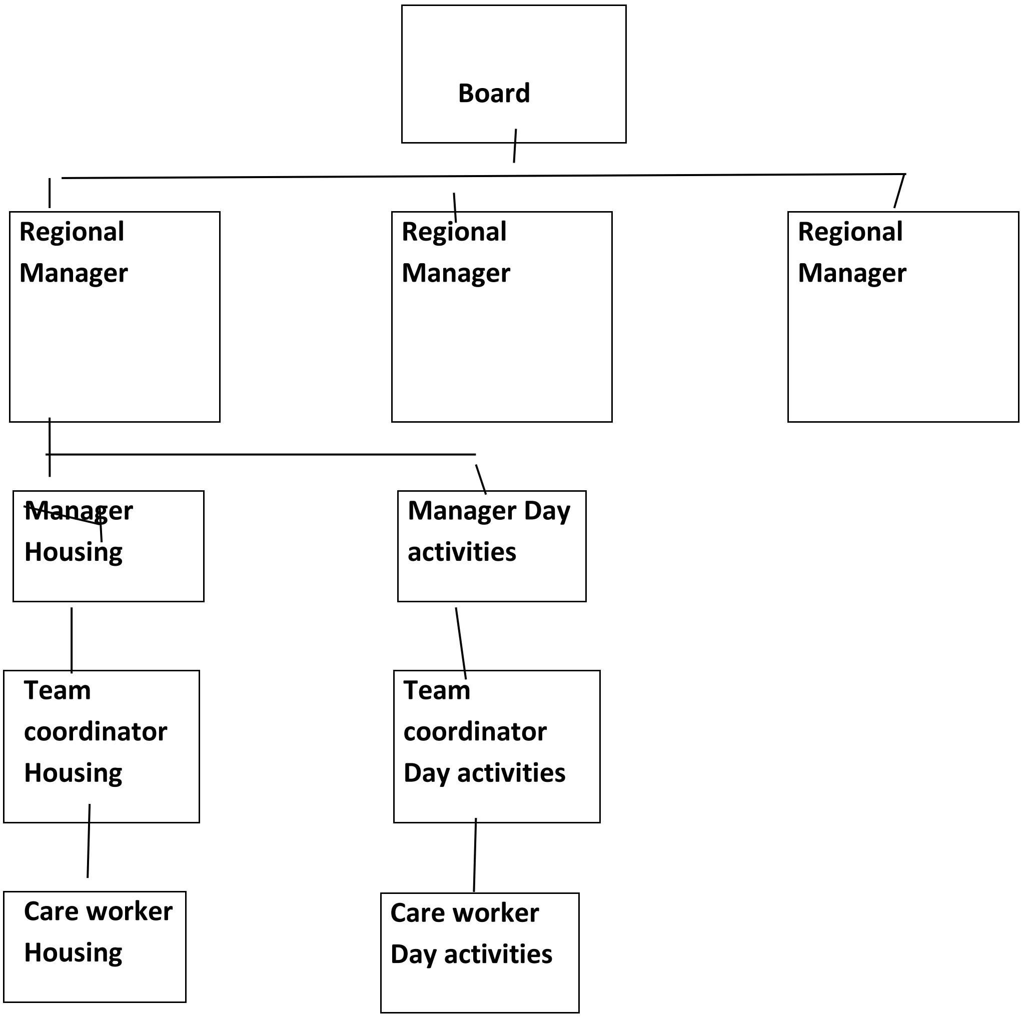
Chapter 15 (PR 14)

Necessary conditions of a support organisation from a client perspective and organisational perspective

15.1Introduction

Care and services for people with a mental handicap are based on an organizational form of supply-oriented care. The structure of care has a number of hierarchical layers.

Below an example



In addition to the strong hierarchical stratification, there is also a separation of functions between living and daytime activities. The aspect of free time can be included in both the work domain of living and daytime activities.

The organization of care takes place in groups, both with regard to housing and day-to-day activities. The client's freedom of choice is limited because they depend on the facilities and activities of the care institution.

The division of the organization into sectors and the stratification of the organization form a limitation when responding to questions from clients. Many topics require a decision from executives or regional managers. Subsequently, the decision must be sent to the executive care employees via the layered structure. A lot of time can be lost with this.

15.2 Support

With support, the support and guidance is directly related to the care needs of the client. Decisions regarding support requests should be made as low down as possible within the organization.

Support requires a different form of care organization. In the “old situation”, care and services are often geared to the organizational structure. In the case of support, the organizational structure must be geared to the care and services to be provided.

The organization of support can be represented as follows:

The client is central in in the middle of a circle.

The support provision (support worker) is in the second circle.

The organisation is in the outer circle.

15.3 to a support organization

A support organization can be developed as follows.

It is important that concrete efforts are made to realize the core values of John O’Brien. The care organization must ensure that there is active support from the support employee to the client in his direct (daily) contacts based on these principles. The role of the support professional is essential. The responsibilities and authorities of the individual support professional and teams of support professionals will have to be worked out. Teams play a central role in organizing and providing the required support. The responsibilities lie low in the organization with the teams and the support employees that belong to them (support circles). The decisions are made directly in the vicinity of the client within predetermined frameworks, which are mainly of a financial nature and based on the care indications of the client and the agreed care.

A structure has been chosen that is characterized by fewer hierarchical layers. A support circle must be considered capable of independently providing support to a number of individual clients in all areas of life. This means that there is no longer a separation between living and daytime activities.

The support circle includes an integrated approach and is managed by a support team. One team member is the coordinator support and is working together with the other support professionals.

The support circle can be seen as the coordination center from which support is offered to a number of clients (approx. 10 – 18). Within this circle, the care and services are coordinated with a coordinating support employee as the point of contact and coordinator for the individual client. The support circle is an independently functioning unit focused on the implementation of the care and services. In this set-up, the client receives personalized support, regardless of the area of life involved and regardless of where the client resides. The client is not shown in the above diagram. There is a one-to-one relationship between the client and the support employee. However, a support employee can support several clients. For example, the client can participate in a community center in the vicinity.

There is a team leader within the support circle. He is part of the team. Part of his time is devoted to coordinating team and personnel matters. The rest of his time is spent on support duties.

A number of support circles are managed by a manager. It is also conceivable, depending on the span of control, to scrap the managerial level in due course and to have the support circles fall directly under the regional manager. At the level of the support circle, certain tasks of the manager (finance, planning, etc.) will then have to be delegated to the t