



【Summary】 Factors influencing the quality of life of people with intellectual disabilities in Denmark and Japan:

From the perspective on personal and environmental characteristics



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If you have any questions and need more information about the current study, please contact me (e-mail): mizuho.amigo@gmail.com

Any comments and suggestions would be most welcome!

Introduction

The pursuit of happiness and good life is a nature of human beings. However, the conditions of life and society are always changing. The growing attention being paid to the idea of quality of life (QOL) for a variety of groups, including the general population, the elderly, those with physical and mental illness, and people with disabilities, indicates the importance of both material living conditions and subjective perceptions of the QOL to improve people's lives (Schalock & Verdugo, 2013; Theofilou, 2013; Helliwell, Layard, & Sachs, 2017; OECD, 2017). The measurement of QOL is important in identifying the inequalities in terms of experiences on the QOL and informing the subjective and objective situations of people's lives to public policy (OECD, 2017) or improving support and practices in the cases of people with intellectual disabilities (ID) (Schalock & Verdugo, 2013).

Why compare QOL between Denmark and Japan?

There are two main reasons that I compared the QOL of people with ID in Denmark and Japan. The first reason is the difference of realization of 'a normal life' between Denmark and Japan. Although living conditions of people with ID have been improved in some aspects in each country because of the introduction of the idea of normalization¹ and paradigm shift of a disability, it is not well-known how people with ID enjoy a normal life from the current QOL perspective in Denmark and Japan. Second, it is important how an idea of independence are realized for the QOL of people with ID. Each country emphasizes the independence differently, either housing or work. It is important for future policies and practice in the field of intellectual disabilities to explore positive and negative aspects of the current situations of independence of people with ID in Denmark and Japan.

More specifically, people with ID in Japan are not completely supported as individuals or adults in the social system. Many people with ID still live with their families even after they grow up, and the independence from family tends to happen after they get a regular job or good money or when family can no longer take care of their children with ID. In particular, there are several issues on the living conditions of people with ID: people with ID have poor opportunities to participate in leisure activities, family budgets of people with ID and their families are low or poor, and even after people

¹ the idea of normalization is 'not to make people with disabilities normal, but to provide normal living conditions, including housing, education, work, and leisure, with people with disabilities as same as people without disabilities' (translated by Nakazono, 1978; Bank-Mikkelsen, 1976)

with ID move to group homes and residential facilities, they still depend on families' care (Inoue, 2013).

Why QOL is important? (Previous studies)

QOL is not a new topic, but it is currently important from human rights perspective as shown in the United Nations Convention on the Rights of Persons with Disabilities (2006). Previous studies have shown that several aspects of the QOL such as self-determination, social inclusion and rights are universally important, and also culturally unique. In addition, it is important to find factors that influence the QOL of people with ID to enhance their QOL. Previous studies show that people with mild ID have better QOL than people with severe ID (e.g., van Loon, Van Hove, Schalock, & Claes, 2009). Other studies show that community-based day and regular work settings (e.g., García-Villamizar, Wehman, & Navarro, 2002), and ordinary housing settings are vital to better QOL (e.g., Claes, Van Hove, Vandeveld, van Loon, & Schalock, 2012). It is generally true that participation in regular or ordinary environments enhance the QOL of people with ID; however, studies show that the current regular environments are not always enough for the QOL of people with ID, particularly in regard to developing close relationships with others (e.g., Lysaght, Petner-Arrey, Howell-Moneta, & Cobigo, 2017). In addition, support by staff members is important for improving the QOL of people with ID, particularly in terms of participation in activities for people with severe ID (e.g., Jones et al., 1999), relationships of people with ID (e.g., van Asselt-Goverts, Embregts, & Hendriks, 2013) and self-determination (e.g., Nonnemacher & Bambara, 2011). However, there were few studies on relationships between professional support or daily practice and other QOL domains such as personal development and rights. Therefore, it will be beneficial to explore the relationships between professional support and QOL domains, considering how staff members balance individual aspects and environmental aspects of the QOL, for practice as well as model development.

Purpose

The purpose of the present study was to gain a better understanding of the current situations and experiences of the quality of life (QOL) of people with intellectual disabilities (ID) in Denmark and Japan through the reports of people with ID and their staff members, and to clarify personal and environmental factors that influence the QOL of people with ID.

Research Question:

How do people with ID and their staff members in Denmark and Japan perceive or experience the QOL of people with ID?

Sub-questions:

1. What are the components of QOL of people with ID in Denmark and Japan?
2. What factors enhance or limit the QOL of people with ID in Denmark and Japan?
3. In particular, how do staff members in day arrangements enhance the QOL of people with ID in Denmark?

Theoretical framework

I used a framework of eight-domain model of QOL by Schalock and Verdugo (2002) in the study (Figure 1). The main characteristics of this model is a multidimensionality of QOL which includes eight aspects. It is also influenced by an ecological model of disability, which defines a disability occurs by interaction between a person and environment.

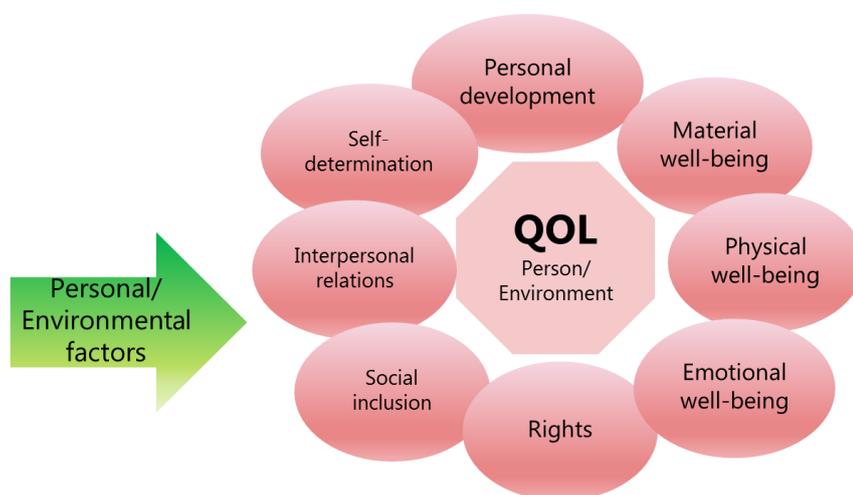


Figure 1 Eight-domain model by Schalock & Verdugo (2002)

Method

The present study employs mixed-method to gain a better understanding of the current situations of QOL of people with ID in Denmark and Japan.

Quantitative Method

QOL assessment was conducted using the Personal Outcomes Scale (POS: van Loon et al., 2008) for people with ID and their staff members to explore the QOL components and potential factors that enhance the QOL.

Participants

Participants were 116 people with ID and 76 staff members in Denmark (Table 1, 2), and 128 people with ID and 27 staff members in Japan (Table 3, 4). Information on ID levels were obtained

from staff members, and ID levels in Japan were classified into two groups (severe or mild/moderate ID) based on the official certification system of ID levels in the local government.

Table 1 *Participants characteristics of people with ID in Denmark (n = 116)*

Characteristics	Total (n=116)		Self-report (n=102)		Report of others (n=101)	
	n	%	n	%	n	%
Gender						
Female	46	39.7	43	42.2	42	41.6
Male	70	60.3	59	57.8	59	58.4
Age(Intervals)						
18-29	46	40.7	43	42.2	38	37.6
30-39	26	22.4	25	24.5	25	24.8
40-49	17	14.7	16	15.7	15	14.9
>50	27	23.3	18	17.6	23	22.8
ID levels						
severe	20	17.2	11	10.8	20	19.8
moderate	35	30.2	31	30.4	31	30.7
mild and borderline	61	52.6	60	58.8	50	49.5
Day arrangements						
Day centre	47	40.5	38	37.3	42	41.6
School	23	19.8	23	22.5	23	22.8
Sheltered employment*	32	27.6	32	31.4	25	24.8
Regular work	4	3.4	4	3.9	4	4.0
Job training under STU**	1	0.9	1	1.0	1	1.0
No day arrangement	9	7.8	4	3.9	6	5.9
Living arrangements						
With family	17	14.7	17	16.7	14	13.9
GH with night watch	51	44.0	37	36.3	45	44.6
GH without night watch	22	19.0	22	21.6	21	20.8
Independent	26	22.4	26	25.5	21	20.8
Living area						
Bornholm	16	13.8	11	10.8	10	9.9
Copenhagen	80	69.0	71	69.6	71	70.3
Odense	20	17.2	20	19.6	20	19.8

Note. GH = group housing; * This includes work inside/outside sheltered workshops which are run by public or private sectors. ** 'Særligt tilrettelagt ungdomsuddannelse' in Danish. This is secondary education for young people with special needs and 3 years free program.

Table 2 *Participant characteristics of staff members in Denmark (n =72)*

Characteristics	<i>n</i>	%
<i>Gender</i>		
Female	35	48.6
Male	37	51.4
<i>Age(Intervals)</i>		
20-29	13	18.1
30-39	17	23.6
40-49	18	25.0
50-59	19	26.4
>60	5	6.9
<i>Qualification(multiple answers possible)</i>		
Social worker*	47	65.3
Health worker**	2	2.8
Occupational therapist	1	1.4
Teacher	5	6.9
Others (designer etc.)	3	4.2
Nothing in particular	15	20.8
<i>Workplace</i>		
Day centre	13	18.1
School	10	13.9
Sheltered employment	7	9.7
Home environment	42	16.7

Note. *Pædagog in Danish.

**Social-og sundhedshjælper in Danish.

Table 3 *Participant characteristics of people with ID in Japan (n =128)*

Characteristics	Total (n=128)		Self-report (n=107)		Report of others (n=105)	
	n	%	n	%	n	%
Gender						
Female	38	29.7	35	32.7	30	28.6
Male	90	70.3	72	67.3	75	71.4
Age(Intervals)						
18-29	39	30.5	34	31.8	32	30.5
30-39	35	27.3	27	25.2	29	27.6
40-49	35	27.3	29	27.1	28	26.7
>50	19	14.8	17	15.9	16	15.2
ID levels						
A(severe)	56	43.8	36	33.6	50	47.6
B(mild/moderate)	71	55.5	70	65.4	54	51.4
borderline	1	0.8	1	0.9	1	1.0
Day arrangements						
Day centre	12	9.0	11	10.3	3	2.9
Work A	22	17.1	22	20.6	21	20.0
Work B	85	66.4	65	60.7	77	73.3
Work C	2	1.6	2	1.9	0	0
Regular work	7	5.4	7	6.5	4	3.8
Living arrangements						
With family	101	78.9	81	75.7	82	78.1
GH with night watch	10	8.0	10	9.3	9	8.6
GH without night watch	4	3.0	4	3.7	4	3.8
Independent	13	10.1	12	11.2	10	9.5

Note. Work A: a work option that provides a regular salary and supervised support with people with ID (sheltered employment); Work B: a work option that provides a small salary and supervised support with people with ID (sheltered employment); Work C: a job training for two years to get a regular job; GH: group home.

Table 4 *Participant characteristics of staff members in Japan (n =27)*

Characteristics	<i>n</i>	%
<i>Gender</i>		
Female	14	51.9
Male	13	48.1
<i>Age(Intervals)</i>		
20-29	6	22.2
30-39	7	25.9
40-49	8	29.6
50-59	2	7.4
>60	4	14.8
<i>Qualification</i>		
Social worker	14	51.9
Care worker	3	11.1
Teacher	3	11.1
Others (e.g., service manager)	3	11.1
Nothing in particular	4	14.8
<i>Workplace</i>		
Day centre	1	3.7
Work A	4	14.8
Work B	19	70.4
Work C	0	0
Support centre for GH	2	7.4
Community living support centre	1	3.7

Note. Work A: a work option that provides a regular salary and supervised support with people with ID (sheltered employment); Work B: a work option that provides a small salary and supervised support with people with ID (sheltered employment); Work C: a job training for two years to get a regular job; GH: group home.

The main instrument

The interview method is often employed to people with ID to promote their understandings of questions and options. The POS (van Loon et al., 2008) used in the present study was developed to measure a person's QOL based on the eight domains and 48 questions. Each question is scored on a 3-point-Likert scale under both of two versions: the self-report and the report of others. The self-report is provided by people with ID. The report of others is provided by individuals who know the

persons with ID well such as parents, relatives, and professionals. Both versions consist of the same items; thus, it is possible to compare the results between them. Scores are decided through a conversational interview between a trained interviewer and the individual with ID and are calculated per domain. This is an example of an item from the self-report and the report of others: Self-report: ‘Do you have the opportunity to express your opinion on what you prefer to do, wear, go, eat etc.?’ (self-determination No. 6) Report of others: ‘To what degree does the person have the opportunity to express what he/she wants?’ (Self-determination No. 6) Choices of answers to these items are the following: (3) = always; (2) = sometimes; (1) = seldom or never.

Procedure

For Danish participants with ID, the self-report of the POS was translated and back-translated between English and Danish by two Danish teachers both of Danish and English. During 2013-2015, the self-report of the POS was administered to 102 people with ID and the report of others of the POS was conducted to 72 staff members by the author in Denmark. In many cases, staff members evaluated more than two people with ID. In addition, staff members participated in the interviews of people with ID as interpreters in most cases.

Similarly, for Japanese participants, the self-report and the report of others of the POS were translated and back-translated between English and Japanese. During 2015-2016, the POS was administered to 107 people with ID and 27 staff members in Japan. In many cases, staff members evaluated several people with ID, and in some cases, staff members participated in the interviews of people with ID to make them feel comfortable. In addition, picture cards of all questions and options made by the author were used depending on individuals both in Denmark and Japan.

Analyses

Statistical analyses including factor analyses, ANOVA, and non-parametric statistics were conducted to explore QOL components and factors that influence the QOL of people with ID.

Qualitative Method

An ethnographic study including participant observation, semi-structured interviews and POS interviews was conducted in Denmark to explore experiences of day activities and work of people with ID during 2016-2017 after the completion of quantitative studies in Denmark and Japan.

Participants

Participants were three people with ID and three staff members in a day centre, and four people with ID and five staff members in a community-based workplace in sheltered employment in Denmark (Table 5, 6).

Table 5 *Participant characteristics of people with ID at the day centre and the workplace*

	Participant	Gender	Age	ID levels	Other main disabilities
Day centre	Frederik	Male	45	Severe	Cerebral palsy, eplepsy. He usually uses a wheel chair when he moves around.
	Olivia	Female	48	Mild	Physical disability, eplepsy. She always uses a wheel chair. She got a brain damage since 14 years old due to brain tumor.
	Karla	Female	72	Moderate	Nothing particularly, but she gets rheumatism.
Workplace	Julie	Female	26	Moderate	—
	William	Male	27	Mild	Autism
	Jonas	Male	25	Severe	Autism
	Isabella	Female	37	Mild	—

Table 6 *Participant characteristics of staff members at the day centre and the workplace*

	Participant	Gender	Age	Educational background	Working period in the current place
Day centre	Sofia	Female	44	Pædagog	14 years
	Victoria	Female	57	Pædagog	12 years
	Anna	Female	58	Pædagog	23 years
Workplace	Celina	Female	59	Teacher	4 years
	Simon	Male	56	Electrician	10 years
	Maja	Female	49	Pædagog	5 years
	Daniel	Male	40	Secondary school	5 years
	Laura	Female	26	Secondary school	1 year

Data collection

Participant observation. All possible activities of participants with ID and their interactions with others including staff members, colleagues, other people from the local community during working hours and day time were observed once a week for 10 months at each place focusing on the eight core QOL domains (Schalock & Verdugo, 2002). Observations were documented in field notes which included not only observations of all occurrences related to support and the QOL but also reflective comments of the author. In addition, pictures of daily activities and work of people with ID were taken to help to write field notes getting permission.

POS interview. For the QOL assessment, interviews using the self-report of the POS (van Loon et al., 2008) were conducted with people with ID twice in the beginning and in the end of the study at each place.

Semi-structured interview. For interviews with staff members, an interview guide was made including some questions of support situations of individuals that participated in the POS interviews, their QOL and general support views based on previous studies (Petry, Maes, & Vlaskamp, 2007). Interviews with staff members were audio-recorded and transcribed.

Analyses

The results of the POS interviews of each participant were described to understand the individuals' QOL before and after the observation. All field notes and transcriptions of interviews were analyzed using thematic analysis (Braun & Clarke, 2006) framework: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Data from the day centre and the workplace were analyzed respectively. The codes were mainly divided into two contents, which were 'experiences of activities/work and QOL' and 'support at the day centre or the workplace.' After the former codes were grouped into each theme, the relationships between themes and the QOL domains based on the model by Schalock and Verdugo (2002) were examined. Consequently, themes were grouped into each QOL domain with considering relationships among QOL domains. Themes based on obtained latter codes were grouped into high-order categories to clarify the relationships among themes. Moreover, relationships between the former themes categorized into QOL domains and the latter themes relative to support were examined.

Ethical Consideration (for quantitative and qualitative studies)

The ethic committee of Hiroshima University approved the research. The principles of the Declaration of Helsinki (World Medical Association, 2013) were guaranteed. Further, the author

completed the e-learning course of ‘For the Sound Development of Science -The Attitude of a Conscientious Scientist-’ (Japan Society for the Promotion of Science, Editing Committee “For the Sound Development of Science”, 2014). All participants were presented with informed consent forms and explanation of the study by the author before the data collection. All participants were informed that participation was voluntary, thus, they could decline to participate in study anytime. When people with ID could not express their opinions, the author or their support workers contacted with their family members or guardians, and then got agreements from them. The forms were signed by all participants. For confidentiality, the names of participants in the quantitative study were recorded using initials and the numbers, and the names of participants in the qualitative study were changed to fictitious names when writing down to the field notes and in the thesis and this report. All data were stored in the password-protected computer.

Results

1. QOL components of people with ID in Denmark and Japan

Danish data showed three domains – emotional & physical well-being, material well-being, and self-determination – as QOL components of the self-report (Figure 2), and two domains – personal development and social participation – as QOL components in the report of others (Figure 3). Japanese data showed two domains – social network and material well-being – as components of the self-report (Figure 4), and three domains – physical well-being, emotional well-being, and material well-being – as components of the report of others (Figure 5). Well-being and social connections were common QOL components in Denmark and Japan, and personal development and self-determination are only found in Denmark. The results also show different perceptions on the QOL of people with ID between people with ID and their staff members in both countries.

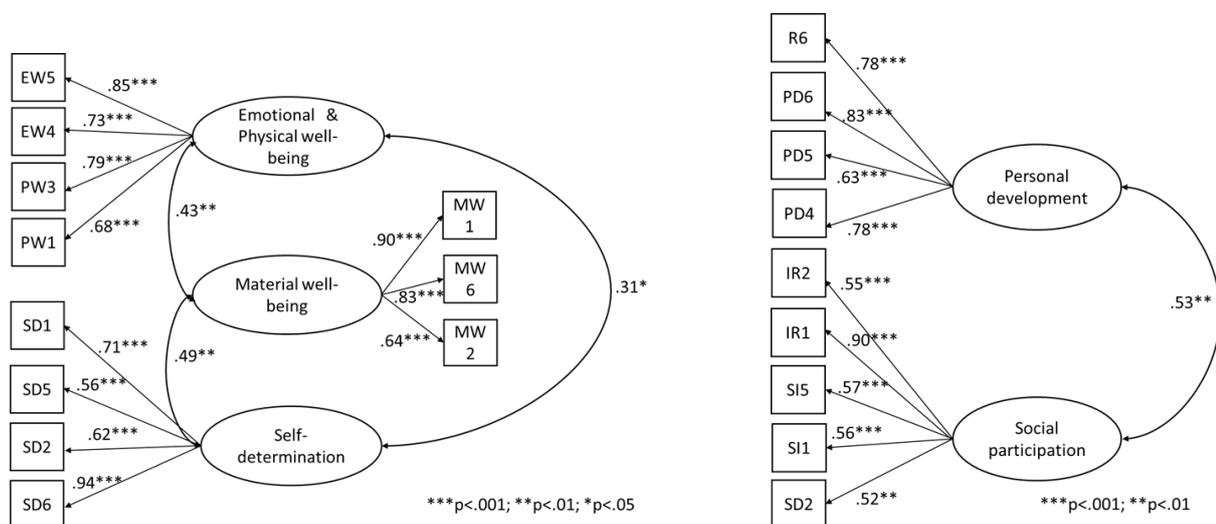


Figure 2 Three-domain model (self-report: Denmark) Figure 3 Two-domain model (report of others: Denmark)

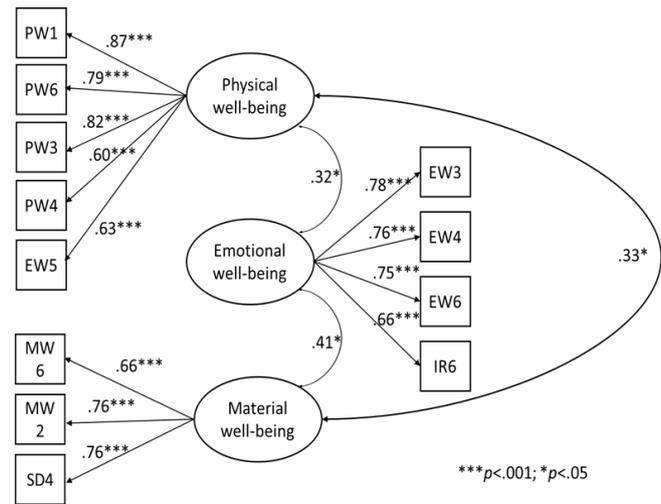
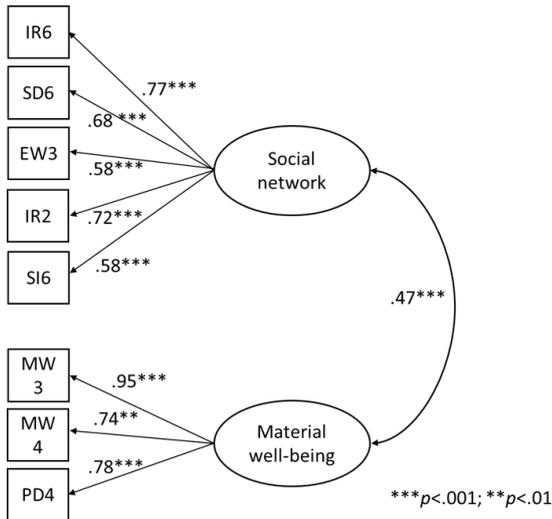


Figure 4 Two-domain model (self-report: Japan)

Figure 5 Three-domain model (report of others: Japan)

2. Factors influencing the QOL of people with ID in Denmark and Japan

The severity of ID levels influenced several QOL domains, positively and negatively. For instance, people with moderate to severe ID reported better emotional & physical well-being than those with borderline to mild ID in Denmark (self-report: Figure 6). Similarly, people with severe ID showed better physical well-being and material well-being than those with mild to moderate ID in Japan (report of others: Figure 7, 8). In contrast, people with moderate to severe ID had lower self-determination (self-report), lower personal development and lower social participation (report of others) than those with borderline to mild ID in Denmark.

Day arrangements and living arrangements also influenced several QOL domains in Denmark. The more independent living arrangements enhanced self-determination of people with ID (Figure 9), and schools and sheltered employment provided better opportunities for personal development of people with moderate to severe ID than did day centres in Denmark (Figure 10).

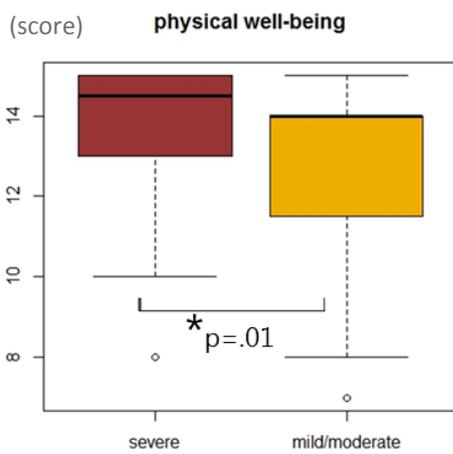
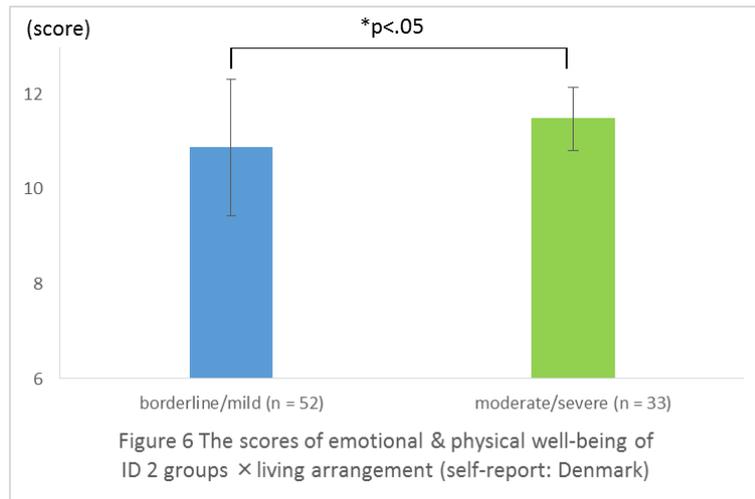


Figure 7 The scores of physical well-being of ID two groups (report of others: Japan)

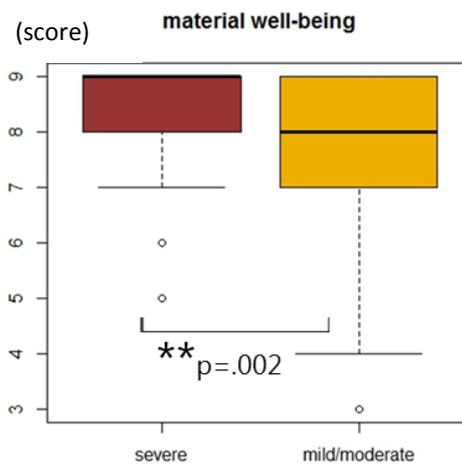
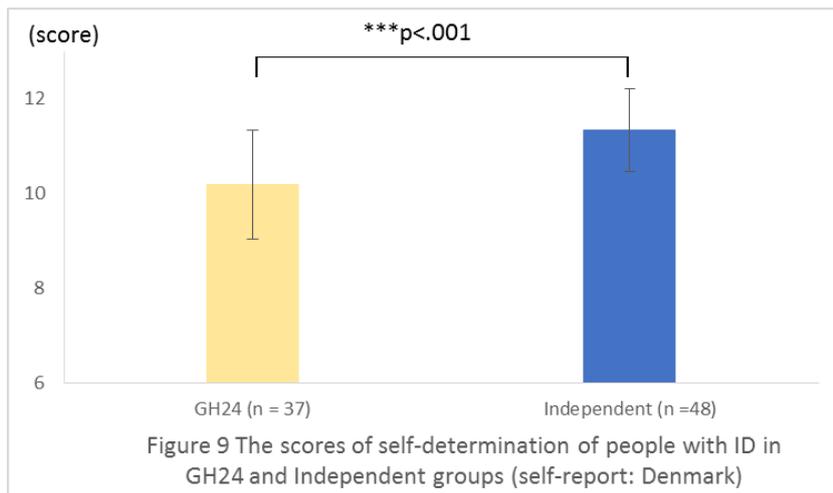
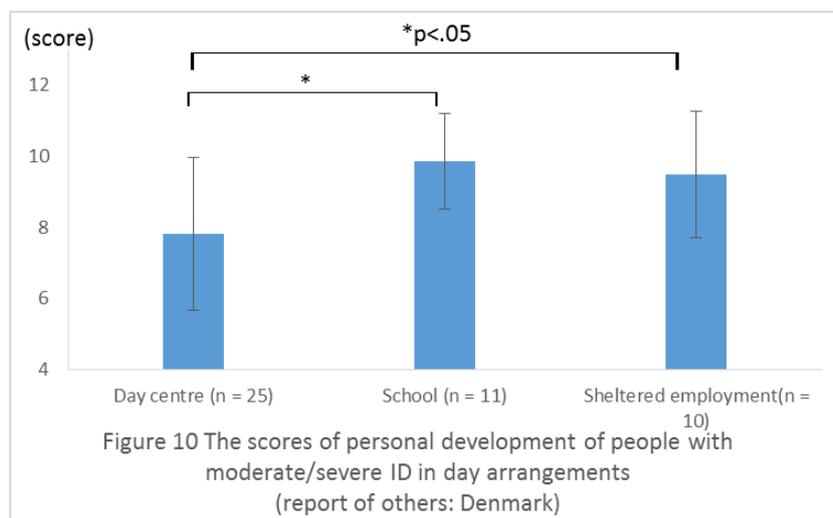


Figure 8 The scores of material well-being of ID two groups (report of others: Japan)



Note. GH24: group housing with 24-h support;

Independent: living independently and group housing without night watch



3. Support and QOL

3.1 Examples of the POS interviews

Day centre

A case of Olivia: Olivia joined in the POS interview three times in 2014 (for a quantitative study), 2016 and 2017 (Figure 11). When she seemed to be confused with her memories, the questions were asked again in the next interview. She thought that the most important support for her was ‘to wear clothes.’ She missed her dead mother, and she was dreaming of ‘mother...every time,’ ‘but I know it’s difficult to go back to the past (2016).’ Overall, the scores improved in 2016 after she moved to another group at the centre. For instance, she had better motivation for making activities and showed interests to learn sewing in 2017 (personal development: PD). She felt she had good friends at the centre and home in 2016 and 2017, which she did not express in 2014 (interpersonal relations: IR). She has lived in the same group housing, but she said that it was possible to have a cat at home because some residents had (2017), although she thought that it was not possible in 2014 (rights: R). She was not in a good condition in 2017, ‘I am tired with people around.’ Staff members asked her where she could be relaxed, and she said, ‘My bed’ (emotional well-being: EW). In addition, she sometimes had some pains at her hand and leg in 2017 (physical well-being: PW). She sometimes went shopping with staff members at home, but she did not interact with other people except for staff members and people with ID at day centre and home, and her family members (social inclusion: SI).

Workplace

A case of Julie: Julie joined in the POS interview three times in 2014 (for a quantitative study), 2016 and 2017 (Figure 12). She said about the positive aspects at work ‘to have *hyggelig* time and

making a joke with others.’ She was interested in using a machine and motorbike at work. She also liked to join in a music band after work where staff members and her colleagues played together. She learned a lot not only at work but also at music (PD). For instance, she became to be capable of expressing herself better and better (SD). She lived independently with support from her father and staff members (R). She thought, ‘it is exciting as a whole. I can do more by myself. But I feel unsafe on weekends because some people are drinking too much in the town, and I know some news about rape and something bad. So I try not to go out at night on weekends.’ She also said, ‘Life is better except for relationships with my father’ (2017), although she talked about her experiences such as bullying at school and dilemma about her own disability in 2016 (EW). She felt she had enough money (material well-being: MW). Her father helped her to take care of her economy. She was thinking about moving out to another apartment someday because, for instance, her neighbor was noisy.

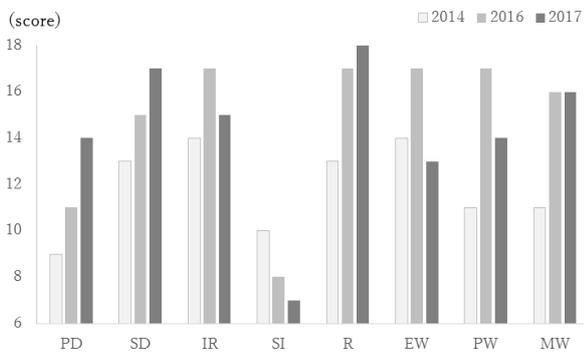


Figure 11 Eight domains scores of the POS (Olivia)

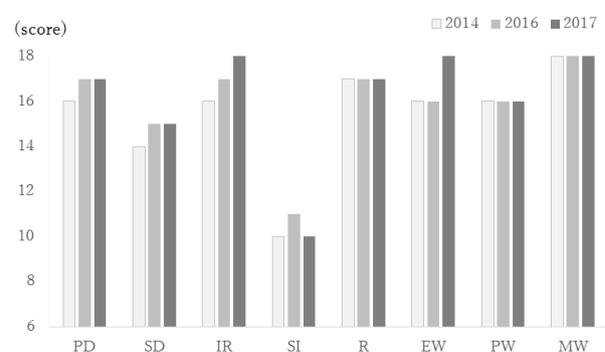


Figure 12 Eight domains scores of the POS (Julie)

Note. PD: personal development; SD: self-determination; IR: interpersonal relations; SI: social inclusion; R: rights; EW: emotional well-being; PW: physical well-being; MW: material well-being

3.2 Experiences of day activities/work and the QOL

Day activities and work at the day centre and the workplace influenced several QOL domains except for material well-being.

Day centre

Field notes: Olivia and a student were making a dessert with lots of fruits in the kitchen. This was called Olivia’s food project. Sofia (staff) explained that Olivia would have a kind of work as a ‘kitchen helper’ in this project. At 2:00 pm we all enjoyed the dessert that they made in the morning with tea or coffee. –personal development

Figure 13 shows relationships among the QOL domains based on the obtained themes at the day centre. Relationships are shown with arrows between domains. All domains might relate each other, due to a possibly that the author might have missed observation of some parts of daily life. Day

activities were mainly divided into two categories: activities organized by staff members and activities of daily life. All three participants, Frederik, Olivia, and Karla, had high needs on health due to severity of physical conditions and age. Activities related to keeping healthy were important not only for health itself but also for keeping their independence (①PD-PW), therefore they engaged in daily tasks and took care of themselves to the extent that they could, as well as participated in specific support programs such as physiotherapy. Each participant was motivated to participate in organized activities. For instance, Olivia liked to work on cooking, and Karla and Frederik liked creative activities. They felt joy and achievement by participation in such activities using their skills (②EW-PD). Participation in organized activities was based on individual free choice (③PD-SD). Sometimes, participants chose to join in activities, but sometimes they did not (④SD-R). There were possibilities to participate in activities outside the centre, such as life-long education or a job opportunity (⑤SI-SD). Karla was happy to participate in a class for learning health with a day centre staff member and other people with ID from different places (⑥SI-EW). Olivia and Frederik, showed interest in working outside the centre, but it was currently difficult for them to get an opportunity because of some reasons; high support needs and limited staff time (⑦SI-R). Participants experienced both positive and negative relationships with others in the centre, and they accepted an agreement (e.g., sitting at a table until others finish lunch) and some suggestions (e.g., a way of speaking and behaviour to others) by staff members to be together (⑧IR-SI) and respect each other (⑨IR-R, SI-R). Sometimes it was troublesome for people with different needs to be together, however, participants and others especially enjoyed being together in special events, such as parties (⑧). In addition, participants enjoyed being together with staff members and others by working together in organized activities and having fun (⑩IR-EW). When participants expressed negative feelings and moods, their feelings were acknowledged and addressed by staff members (⑩).

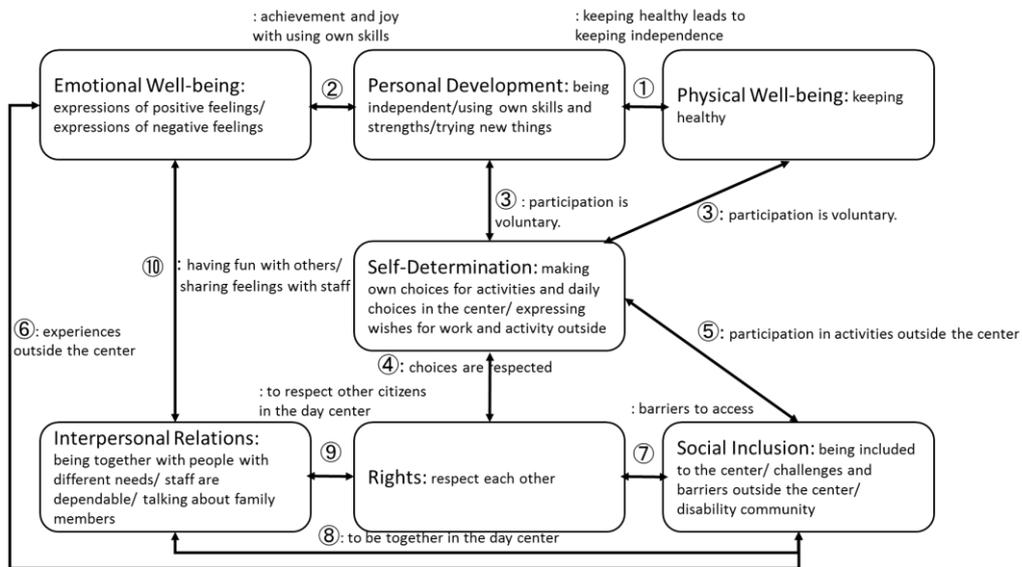


Figure 13 Relationships among the QOL domains at the day centre

Workplace

Simon (staff): 'Julie does not like to make a mistake. No one does, but that's a way to learn. You have to make a mistake and then learn, and mistake and learn. But I can see now, she is working on music, she is very patient, and Daniel (staff member who started music activity) is very patient, and the others are very patient around. In this situation, I think it's a new arena, for Julie to develop as a person, not skills, but after personal skills you can develop some working skills.'—personal development

Figure 14 shows relationships among seven QOL domains. Most tasks that participants were engaged in were directly related to the local community. Some tasks were completed for the guests from the local community, and others were collaborative work with animals and nature. Therefore, it was easy for participants to be able to see the results of their efforts as well as their connection with the local community (①PD-SI). These work environments enhanced a feeling of pride and self-confidence for participants, although it depended on individuals (②PD-EW, SI-EW). Most of the tasks were physical work in nature, which was attractive for young people with ID such as Jonas. He felt that this kind of work suited for him because he could use his muscle and he also felt good with working in nature (③PW-EW). The leader's proposed daily tasks were normally accepted by people with ID, but it was respected for participants and other people with ID to express their preferences, including refusal (④SD-R). If participants wished, they had opportunities to try new tasks and get a qualification as tractor driver (⑤PD-SD). Participants worked together and helped each other to accomplish tasks (⑥PD-IR) and had a good time with colleagues (⑦IR-EW). Isabella had only experienced regular workplace for a short time, and she felt difficulties with

developing relationships with colleagues there. Further, participants and other people with ID could feel a sense of belonging to the workplace and express their ideas by participating in meetings and events, as well as daily tasks (⑧SI-SD, SI-IR). Everybody was expected to listen to others' ideas and respect each other in the meetings (⑨SI-R). To have work was an important part of independent life for participants, and they faced some limitations in terms of bigger decisions in their lives. For instance, William was not allowed to live with his son (⑩SD-R). Isabella could not have a pet in spite of her wish. Both of them had a hard time in their lives because others insisted that they give up what they really wanted (⑪R-EW). Julie got her wanted life, living independently, however, she might feel lonely (⑫SD-EW).

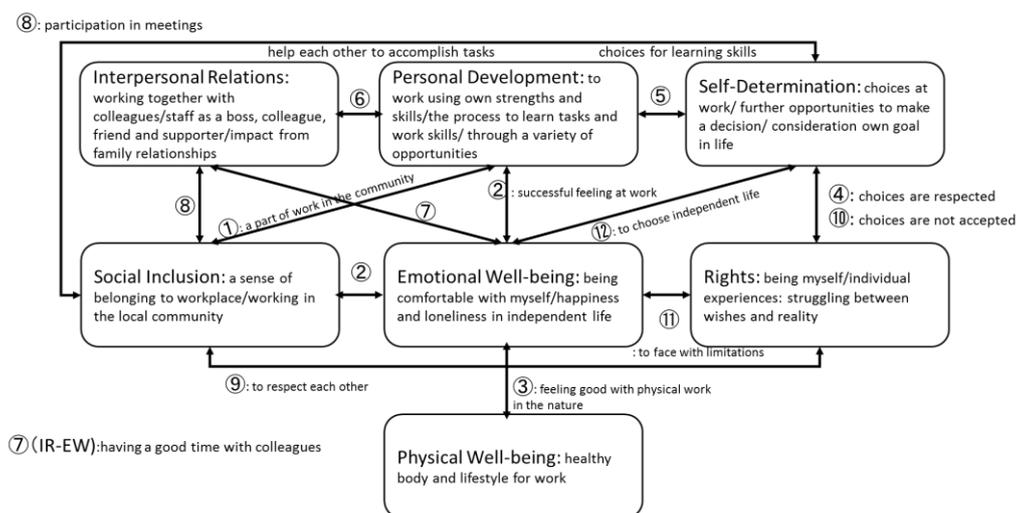


Figure 14 Relationships among the QOL domains at the workplace

3.3 Support to enhance the QOL

Day centre

Victoria (staff): 'Anderkendelse. I tell her, she (Karla) was good at making it, which we make together. She is very good at, she is good at listening, and she is good at coming an idea while we are making. Doesn't matter whether my hands make it. When I tell her, "you are very good at...doing this, coming the idea" then she is... growing and happy.' -equality

Supports were provided to enhance several QOL domains; however, at the same time, staff members faced a dilemma as they sought to support individuals. Each theme was categorized into two high-order concept: **【knowledge & values for action/practice】** and **【support strategy/practical support】** to clear the relationships between themes.

【Knowledge & values for action/practice】

i) *'Understanding of strengths and weaknesses'* mainly influenced four domains: PD, SD, R and EW. Staff members made opportunities to participate in activities (PD) considering what individuals could do and what they might have difficulties with. Providing opportunities of activities led to opportunities of choices and a feeling of achievement and joy of individuals with ID (SD, EW). Individual needs were understood and updated day by day, for instance, by listening to their expressions of their needs -which were not fixed forever but rather fluid (R). However, staff members faced a dilemma as they sought to coordinated support the needs of all individuals.

ii) *'To fulfil his/her wishes'* influenced five domains: PD, SD, SI, R and EW, although it depended on individuals what domains were more focused. Staff members considered individuals' wishes as well as their needs for providing activities. The point is that individual wishes could be realized and individuals could feel successful through the process. For Frederik, past experiences of work outside the centre, which were coordinated by staff members in response to his wishes, gave him opportunities to use his skills and try new tasks (PD). Importantly, he decided by himself to participate in work activities (SD), and had chances to meet people in addition to people with ID and staff members in the day centre (SI). It did not always happen that his wishes and ideas came true due to internal and external reasons, although his wishes and ideas were basically respected by staff members (R) and he enjoyed such new challenges (EW). For Karla, daily organized activities with staff members were her favourites (PD, EW). In addition, she was eager to participate in new activities, such as a special class for learning health, if presented by staff members (SD). For Olivia, working in a real kitchen because it was unrealistic at that time considering her physical and mental conditions, but staff members offered a range of creative options. The solution was not her real wish itself, however, she was excited about working in the kitchen in the day centre (PD). She wanted to work there when it was possible for staff members to arrange it (SD) and felt joy with it (EW). Support to fulfil wishes meant the way to respect of individuals (R).

iii) *'Equality'* was a basic attitude of staff members, but mainly influenced two domains: R and EW. Even though participants had very limited skills for work and activity, staff members found something good that individuals had and made them feel achievement and pleasure (EW). Tasks were accomplished by collaboration of everyone that participated. Staff members valued that no individuals, including staff members, had abilities or skills that were superior or inferior to others (R). For Olivia, her kitchen project could be said as imitation work, yet she understood herself to be doing meaningful work as a kitchen helper and was glad that staff members had created the opportunity (R, EW).

iv) *'Togetherness'* influenced three domains: R, EW and SI. Staff members considered group dynamics so that everybody could be comfortable while staying in the day centre (EW, SI). Individual needs, including individual space, were respected as well (R).

【Support strategy/practical support】

v) *'Using resources for providing support'* mainly influenced PD and PW domains. Staff members made use of resources inside and outside the centre to provide opportunities for participation in activities (PD) as described in case of Olivia's and Karla's projects. At the same time, staff members had a dilemma that individuals' arrangements were not always easy; consequently, those opportunities tended to be limited to a few people and were of low frequency. Further, for Olivia, staff members thought that she needed more specialized support than the centre could provide, considering her disability, but this centre was the best available options for her.

vi) *'Personal care'* influenced two domains: R and PW. Personal care was provided to meet basic needs for individuals, and individuals' regular rhythm in daily life and health status were also considered as support (R, PW).

vii) *'Support for independence'* influenced two domains (PD, SD). Staff members thought that it was important for participants and other citizens with ID to take care of themselves as much as possible for their independence and maintaining their body functions (PD). Staff members provided choices to individuals with ID in activities related to daily living as well as organized activities in order to enhance their independence.

viii) *'Support for relationships'* influenced three domains: IR, SI and EW. The role of staff members was important to connect citizens by working together and having fun (IR, SI, EW). Staff members also prevented troublesome interactions in the centre by separating participants and other citizens physically, using environmental opportunities, and counseling each of them about their behaviours.

ix) *'Emotional support'* influenced the EW domain. Staff members usually gave a positive mood around to citizens by having fun and having conversations as well as using environmental opportunities. Staff members acknowledged negative feelings of individuals, as for example when Karla and Olivia experienced the loss of loved ones.

x) *'Something special in daily life'* influenced three domains: EW, IR and SI. Staff members used music to make good moods for individuals and also used it in special events such as a birthday party. Not only music but also special events were opportunities to share exciting moments with others, except for some people who preferred their own regular routine (EW,IR,SI).

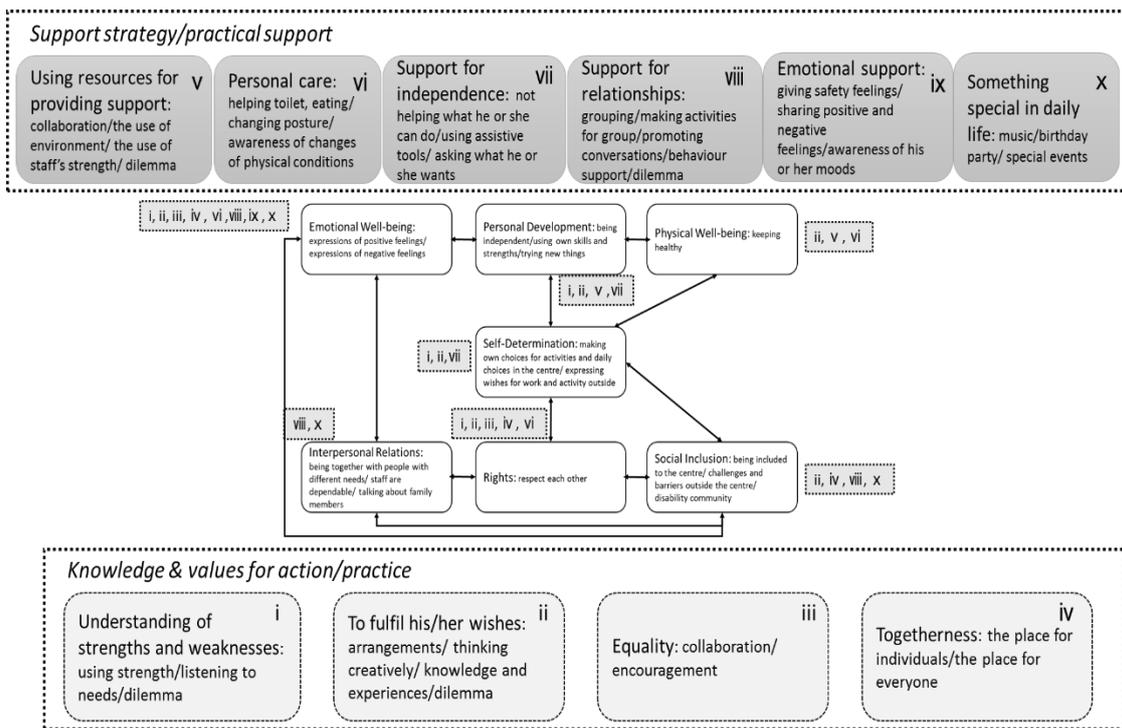


Figure 15 Relationships between support and the QOL domains at the day centre

Workplace

Celina (staff): 'By giving him (Jonas) some tasks that he can handle, and then you know, he feels successful when he goes home, and to say to him "you had... better good jobs, you were brave today," [...] but he feels proud and then the best thing is you can support his proudness, you know?' –giving a task

Figure 16 shows relationships support and the QOL domains. Each theme of support influenced more than one QOL domain. The need of each support depended on individuals; therefore, domains influenced by support were different from individual to individual.

【Knowledge, values & minds of staff members】

i) *'Understanding of strengths and weaknesses'* influenced the PD domain. Staff members learned and understood individuals' strengths and weaknesses by working together with participants with ID. All four participants already had some regular tasks since they had been working for a while; therefore, they and their staff members knew how to work together in regular tasks. Each participant had something they were good at; however, staff members had to make sure the points and parts which needed support were in order to accomplish a task.

ii) *'Relationships are beneficial'* influenced three domains: IR, SI and R. The workplace accepted a variety of people with disabilities, which led to development of relationships among employees and also helped to develop staff members' knowledge on disability (IR, SI). The relationships

between employees and staff members were relatively gentle, which means supports were provided rather flexibly and naturally beyond work-related tasks. It was treated as friends helping friends (R).

iii) *'Good energy for independent life'* influenced four domains: PD, SD, SI and EW. Most participants lived independently and most young employees probably expected to start living independently sooner or later. Staff members emphasized improvement of employee skills at work that would strengthen the foundation for independent living (PD). Staff members also provided opportunities of choices at work, and work-related communication with staff members, to foster strength of employees to control over their own lives (SD). Moreover, staff members considered that employees who could connect each other at work would also have energy for living independently (SI, EW) so that they felt less lonely.

iv) *'I would like to see people's development'* mainly influenced the PD domain. Staff members focused on personal development of participants, which were not only development at work but also development as a person. As such, staff members regarded it as important to expand possibilities of each individual by using a variety of opportunities.

v) *'Work is important for normal life'* influenced three domains: EW, R and SI. Staff members thought that work gave participants happiness and a comfortable place in society because of the nature of life of human beings (EW, R). All participants were satisfied with the current work and did not particularly want to have a regular job. Staff members mentioned that society could be still hard for people with ID and other people who are 'different' (SI).

【Support strategy】

vi) *'Giving a task'* influenced four domains: EW, SI, SD and PD. Staff members gave a task to participants and employees so that they could have a feeling of achievement (EW) and a part of work and society (SI), to make opportunities of choices (SD) and to improve their skills (PD).

vii) *'To motivate'* influenced PD and EW domains. Participants were basically self-motivated at work, and the prospect of new tasks and projects became a good motivation for many employees (PD). However, staff members needed to encourage some participants and other employees to participate in tasks when they were less positive, for instance, by using humour and working together so that they feel having fun or interests at tasks (EW).

viii) *'Communication support'* influenced three domains: SD, IR and EW. Staff members usually encouraged interaction and communication between employees. In addition, staff members adjusted the way they communicate, depending on individuals. For instance, staff members paid attention to confirm William's mind and feelings because he was not expressive (SD). It was not often, but staff members helped to arrange plans for Isabella and Julie's spare time, and counselling each of them, as needed, when troubles arose (IR, EW).

ix) 'Emotional support' influenced EW, IR and PD domains, particularly for Julie. Staff members provided daily support so that participants could feel successful at work (EW). Julie felt better with herself than before through successful experiences at work (PD, EW), which influenced her perceptions and actions toward her father (IR).

x) 'Working environment' influenced four domains: IR, SI, EW and PW. Participants felt they were a part of the workplace and the community because of the work settings which the workplace was open to everybody and collaborated with other business partners (SI). In addition, participants felt benefits of working in nature (PW). Staff members provided several opportunities that employees could make good relationships each other in special events as well as during regular meetings (IR, SI, EW).

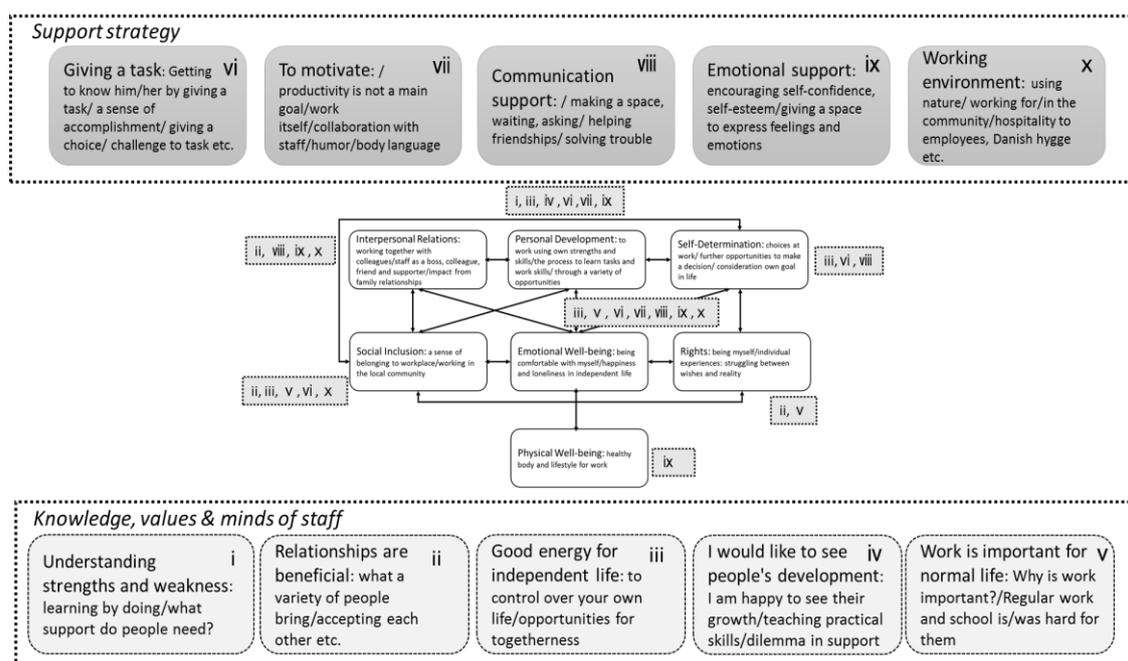


Figure 16 Relationships between support and the QOL domains at the workplace

Discussion

1. QOL components of people with ID in Denmark and Japan

There are several common and different QOL components between Denmark and Japan. Well-being and social connections are common to Denmark and Japan. In contrast, personal development and self-determination are shown only in Denmark, that is, these two domains tend to be more influenced by culture than well-being and social connections. In addition, people with ID and their staff members paid attention to different QOL domains of people with ID. Their perceptions of the QOL of people with ID were influenced by their cultural contexts and support environments. People with ID in Denmark emphasized to control their own lives including taking care of money, which

connects with their happiness and satisfaction. Staff members in Denmark emphasized personal development and social participation to support independent lives of people with ID. These trends may be because basic well-being for people with ID is guaranteed, including housing and living independently in Denmark. In Japan, people with ID emphasized to have a paid job and to contact with friends, staff members, and others in their local communities. Staff members in Japan emphasized well-being of people with ID, including happiness, health, and money. These results may reflect the current situations in Japan that most people with ID live with their families and work in sheltered or regular workplaces. In other words, there is lack of the idea and support of independence including personal development and self-determination in Japan.

2. Factors influencing the QOL of people with ID in Denmark and Japan

Severity of ID levels, both in Denmark and Japan, did not always lead to low personal well-being. The availability of social services was important to support the QOL, including well-being, of people with ID. However, the Danish data shows that people with severe ID tended to have fewer opportunities for self-determination, personal development and social participation than those with mild ID. It is necessary to consider expanding opportunities to participate in daily activities for people with severe ID, and it is also important to examine whether the questions in each domain are meaningful for individuals with severe ID. Environmental factors – such as settings that allowed for more independent living, as well as well-designed work and school options – enhanced self-determination and personal development in Denmark. Living with family helped to maintain or enhance well-being of people with ID in Japan, especially as government-provided social services and financial support were limited. Overall, the quality of their environment had a tremendous impact of the QOL of people with ID. Therefore, in addition to fundamental support according to individual needs, the current study finds that appropriate support to provide opportunities to choose day activities and places to work or live, demonstrate their own skills, and contact with friends and others – rather than simply regular or segregated settings – is necessary to enhance their QOL.

3. Support and the QOL of people with ID in Denmark

By contrasting a day centre and a community-based sheltered workplace, the study showed the relationships between the QOL of people with ID and support by staff members considering interaction of personal and environmental characteristics. Overall, support by staff members influenced seven QOL domains – all domains except for material well-being – at both the day centre and the workplace. In particular, day activities and tasks provided by staff members were opportunities to enhance the QOL, such as personal development and emotional well-being, of

people with ID. It was not always necessary to improve personal skills to enhance their QOL, but it was always important to provide people with ID opportunities to use their personal skills at day activities and work. It is also important for staff members to understand QOL's multidimensionality and, given limited resources, balance between developing personal and environmental approaches to enhanced QOL of people with ID.

Day centre: Activities relative to keeping healthy and maintaining independence were important for the QOL of participants with ID because their physical conditions were getting more severe as they were getting older. Activities corresponding to individual wishes such as life-long education and job internships outside the day centre were also arranged for individuals, although there were several barriers – including shortage of resources, too-few staff members and high support needs of individuals – to realising individualized activities. Staff members at the day centre had support views ('understanding strengths and weaknesses', 'to fulfil his/her wishes', 'equality', 'togetherness') based on rights, which led to the conclusion that staff members considered the tendency of unequal situations of participants with ID in their daily environments and society. In addition, staff members emphasized provision of opportunities to use existing personal skills of people with ID rather than improvement of their skills to enhance their QOL. To this end, staff members used resources (environment) inside and outside of the day centre as they sought to accommodate individual needs and wishes for their daily lives and day activities. The day centre was a place for people with ID, particularly for people with severe disabilities as a whole who usually needed individualized support in many aspects of their daily lives. Staff members had to balance their time between supporting individuals and supporting groups. On the one hand, the strength of a collective environment is that people with ID could receive professional services such as physiotherapy as well as professional support by staff members based on deep knowledge of and experience with people with ID. On the other hand, one of the weaknesses of the day centre was the increasingly limited time available for individualized support, which due both to downsizing of staff members and because many day centre participants required highly intensive support. In addition, small conflicts between some participants and other people with ID in the day centre was inevitable because they did not understand each other's behaviour.

Sheltered employment: Work was important to adults with ID. Participation in several tasks, using their own skills in the community-based working environment, improved their self-confidence and sense of belonging to their local communities as well as their workplace. Although participants had dilemma between their wishes for an independent life and the real constraints on such realization, work and support at their workplace provided opportunities for personal development and connections with others so that they could live increasingly independent lives.

Staff members at workplace had support views ('understanding of strengths and weaknesses', 'relationships are beneficial', 'good energy for independent life', 'I would like to see people's development', 'work is important for normal life') based on an idea of independence and rights considering the relatively young age of the participants. By assigning a task, staff members emphasized that participants could feel achievement and being a part of society as well as to provide choices and enhance personal skills.

Yet, the study shows that people with ID who had high support needs tend to have limited opportunities to participate in activities and make choices, particularly in the day centre, regardless of the severity of their ID. The opportunity for people with ID to choose their places for day activities and work can have a significant impact on their QOL. When staff members provided support that enabled people with ID to participate in activities based on their wishes, these people experienced additional improvements in their QOL, such as more opportunities to use personal skills and a feeling of accomplishment through successful participation.

With regard to supports to enhance the QOL of people with ID, staff members at both the day centre and the workplace considered the interaction between individual and environment aspects of QOL. Specifically, it was important to provide opportunities to use own skills that individuals already had to enhance their QOL regardless of the severity of disabilities, although staff members at workplace also devoted time and attention to improvement of personal skills. Environmental characteristics of the day centre and the workplace influenced the frequency of opportunities for people with ID to participate in day activities or work. People with ID at the workplace regularly engaged in several tasks, whereas day centre participants participated in activities irregularly, depending on arrangements by staff members and individual preferences. Moreover, environmental characteristics of each place influenced social inclusion and interpersonal relations in particular. However, even in the workplace, staff members did not focus on material well-being due to the fundamental guarantee of income via disability pension. As van Loon (2005) points out, support has to be provided flexibly to individuals, support views of staff members and focus of support were somewhat different between the day centre and the workplace because of individual needs and wishes. Support to enhance individual QOL of people with ID needs to be offered in the context of QOLs multidimensionality, which help staff members to know which QOL aspects focused on, given the several limitations of their environment.

Conclusion

Unpacking the multidimensionality of the eight-domain model made it possible to understand the different perceptions between people with ID and their staff members on the QOL of people with ID in Denmark and Japan, the impacts of the support environments in each country, and the role of staff members in enhancing the both personal and environmental aspects of the QOL.

Specifically, in Denmark, personal development as an individual who have an independent life, and social connections with others, such as friends and companies, are important to support an independent life. In contrast, there are limitations to support for self-determination and individual lives in Japan because most people live with their families. In other words, there are many barriers and few models to live independent from families in Japan.

- QOL of people with ID in Denmark and Japan consists of several domains, including well-being and social participation. Specifically in Japan, it is necessary to improve or rethink the contents of personal development and self-determination. These domains are more influenced by culture than well-being.
- In terms of well-being, people with ID are not at a disadvantage because of severity of disability although support is necessary.
- In terms of personal development, self-determination, and social participation, these are influenced by personal and environmental factors.
- Staff members play a key role in determining which aspects of multidimensional QOL would be supported, depending on the situation, and providing support, taking a balance between individual and environmental aspects.

However, there are several limitations of the current study. First, it is not clear about relationships between all eight QOL domains. Second, the findings cannot be generalized due to the contexts of the limited local settings in Denmark and Japan. In addition, due to the limitations of grouping, such as relatively small number of people with severe ID or people living with family in Denmark, and very few people who lived in group homes in Japan, the impacts of personal and environmental characteristics on the QOL might not have been well-demonstrated in the current study. Future research will require inclusion of more people with ID who avail of a wider variety of day or living arrangements. It is recommended that future research on the QOL of people with ID be undertaken as collaborative studies with people with ID, their families and staff members to

apply a QOL assessment to practice at organization and public policy to improve the QOL of people with ID.

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