

The progress of self-advocacy in Taiwan as seen from discussions of leisure activity by people with an intellectual disability

Background

◆CRPD § 30 emphasizes that people with a disability have the equal rights to participate in cultural and leisure activities as those without a disability. In Taiwan, it is one of the obligations of the Government to promote participation in leisure activities by people with a disability, as is written in the 'People with Disabilities Rights Protection Act (PDRPA)' § 52.

◆Several studies have proven the importance of leisure activity in improving Quality of Life (QOL) and in maintaining a stable occupational life for people with a disability. However, most of the opinions examined are from the viewpoints of professionals and family members. In accordance with PDRPA § 52 and CRPD § 30, recently more and more people with disabilities have been claiming their cultural and leisure rights. But there are still fewer voices to be heard from people with an intellectual disability (people with ID).

◆PAPID Taiwan (Parent's Association for People with Intellectual Disability, Taiwan) has been organizing a National Self-Advocacy Network for people with ID that aims to promote and support them speaking up in their own voices since 2008. It has seemed to hardly hear the real voices of people with ID, however, because when people with ID are asked their opinions they turn to get their supporters' permissions to talk. Since 2014, PAPID has tried to change the format of the gatherings to lengthen them from half a day to a whole day in the Network meetings and to separate the participants with ID and their supporters in the afternoon, while still keeping two social workers present as facilitators and supporters to organize the discussion in the meeting.

◆In 2015, besides the two social workers, PAPID invited one person with ID to join as a facilitator and take part in organizing the discussion meetings for people with ID in the afternoon for each gathering. Furthermore, unlike the previous year, the three facilitators tried to let the participants with ID choose that year's discussion topic. In the first meeting, the participants chose 'Leisure Activity' from seven topics* provided by social workers as a reference. (* The seven topics were 'Civic Engagement', 'Living Arrangement', 'Personal Safety', 'Lifelong Learning', 'Transportation/Mobility Support', 'Leisure Activity', and 'Cultural Participation'.)

Purpose

◆To discuss and analyze the progress of self-advocacy in Taiwan by examining the process of the discussions about leisure activity undertaken by people with ID in 2015.

Method

◆The researcher analyzed materials related to the proposal of the project, and the power points, handouts, meeting notes, feedback sheets, videos and photos from the afternoon session of the discussion meetings for people with ID at the National Self-Advocacy Network meeting in 2015.

Position of the researcher

◆The researcher was the coordinator and supporter of the Network from March 2013 to March 2017. In addition to the materials from the meetings, the researcher's observations in the Network are also used in this research.

The process implemented at the Network meetings (in the afternoon session)

◆People with ID from 20 organizations participated in the Network meeting in 2015. Around 21-26 participants with ID (in their 20s to 40s, most with the labeled level of mild to moderate ID, but a few with what is labeled a severe ID) and two licensed social workers as supporters and facilitators (one of whom also served as the coordinator of the Network) attended each meeting in the afternoon. That year PAPID also launched the use of traffic light cards ('red' for stop or disagree, 'green' for agree, and 'yellow' for a question) based on experiences in Japan and Europe.

◆Three facilitators (1 person with ID and 2 licensed social workers) had meetings before and after each discussion meeting. In each discussion meeting, the facilitator with ID would introduce all participants and explain what to do next. Then, the facilitator with ID and 1-5 participants with ID gave an introduction of the topic for that discussion meeting in the first 30 minutes. They were then divided into 4 to 5 small groups to have discussions for 30 - 40 minutes. After these small group discussions the groups gave presentations for 30 minutes. In the last 30 minutes, the participants with ID used round stickers to vote for the assertions with which they most strongly agreed and then filled in the feedback sheet for that discussion meeting. The main process is shown in Figure 1.

◆Before the end of each discussion meeting, the facilitators would announce the topic and discussion points for the next meeting. The coordinator would send the meeting notes to the supporters belonging to each participating organization to forward to the participants with ID.

Figure 1: The process for each discussion meeting



Outcome

◆59 people with ID (141 person-times) in total participated in Network meetings in 2015. The overviews of each meeting are shown in Table 1. There were 4 people with ID who participated six times, and 27 people with ID who attended only once during the year. On the other hand, there were 20 local organizations that participated in the Network that year, but not all organizations would assign representatives to attend every gathering.

◆In the 1st and 2nd events the participants were divided into 4 or 5 small groups randomly. However, the facilitators found sometimes there were almost all new participants in the same group, which caused that group to engage in less discussion. Thus, in the 2nd meeting after the discussion meeting the facilitators recommended PAPID divide the participants with ID according to their traits into different groups in advance.

◆In the 1st meeting, besides these 7 topics, some participants expressed a desire to talk about 'Making friends /Marriage'. The facilitators intended to persuade the participants to discuss 'Civic Engagement' in order to stimulate their awareness of their rights, but failed. 'Leisure Activity' was chosen as that year's topic.

◆In the 2nd discussion meeting, the facilitator with ID talked about her experiences of the meanings of 'Leisure Activity', which were ① to reduce pressure, ② to be able to do some activities she likes, and ③ to promote health. Participants also talked about what they would worry about themselves and what they think the people around them would worry about when they do leisure activities. A summary of this discussion is shown in Table 2. Also, a young man with ID gave introductory remarks about the types of leisure activity. When he asked other participants whether they could give some other examples of leisure activities, there were two males with Autism in their 20s who argued over whether going to a pub is a good thing for over 20 minutes (their arguments are shown in Figure 2). These voices were heard for the first time in this Network since 2008.

◆The outcome of the third, fourth, and sixth discussion meetings are shown separately below. In order to show the original opinions by the participants, the researcher uses the words 'I' or 'We' in the following sections.

Table 1: Overview of each discussion meeting (*pars.=participants with ID. /org.=organizations)

1 st meeting (2015/03/23)	2 nd meeting (2015/04/29)	3 rd meeting (2015/05/27)	4 th meeting (2015/08/26)	5 th meeting (2015/10/21)	6 th meeting (2015/11/25)
Place: Taipei (台北)	Place: Taichung (台中)	Place: Taichung (台中)	Place: Kaohsiung (高雄)	Place: Tainan (台南)	Place: Taipei (台北)
24 pars. /from 20 org.	26 pars. /from 19 org.	23 pars. /from 19 org.	26 pars. /from 16 org.	21 pars. /from 17 org.	23 pars. /from 17 org.
Point: ①deciding on the discussion topic for that year. ②the topic of 'leisure activity' was selected from 7+1 topics by participants with ID.	Point: ①talking about the meaning of 'leisure activity', and the things they worry about ②selecting 3 kinds of leisure activities for deeper discussion from next time. ③the argument about whether going to a pub is a good thing	Topic : Listening to music ◆ 4 participants gave introductory points.	Topic : Going shopping ◆ 2 participants gave introductory points.	Topic : Visiting National Museum of Taiwan History ◆It wasn't organized the separated meeting in this time. Thus, it was not discussed in this research.	Topic : Going to a movie, and reflecting on the discussions held during the year ◆ 1 participant gave introductory.

Table 2: What worries might there be about people with ID when they do leisure activities?

What persons with ID would most worry about themselves	① injury (safety)	② money(cost)	③ time
What persons with ID think the people around them (e.g. parents and supporters) would be most concerned about when they do leisure activities.	① safety	② health	③ money(cost)

Figure 2: An example of an argument by two participants with Autism in the 2nd discussion meeting

SHOULD GO!
Because you can do...

Whether going to a Pub is a good thing

Drink
Dance
Chat
Relax

it relates to ...
Right & Reliance

Mr. A: We are adults. It's our right to go to a pub like other adults. If we are careful of our safety when we go to a pub it is OK. The most important thing is how to make our family trust that we are mature enough to go to a pub.

Should NOT GO!!!
Because you might encounter...

Drinking
Smoking
Drug · Sex
Trouble
Noise

Safety & Cost

Mr. B: It's better not to go to a pub because there are so many problems that may occur. We should avoid encountering these problems. Also, going to a pub costs a lot of money.

Third meeting: When Listening to Music

◆ Some things I should be mindful of:

- When I listen to music in public places or there are others in the same space, I should use earphones and keep the music at a volume which would not bother others. If someone's music is too loud and bothers me, I should tell the person gently.
- When I listen to music while walking, or when I go to a concert, I should pay attention to safety regarding passers-by and cars.
- When I download music from the Internet, I should watch out for computer viruses and copyright infringement. I also need to be aware of the cost and age limitations.

◆ What kinds of support I need/want

- I want a quiet space to listen to my favorite music without bothering or being judged by others. Also, I want to share and listen to my favorite music together with my family and supporters.
- If I listen to music too loudly, or someone wants to talk to me and I don't notice, please tell me gently instead of scolding me.
- I need someone to teach me how to get concert information and how to buy concert tickets.
- I need my family to take me to the concert venue if I don't know how to get there.
- I want to go to a concert with my friends and supporters.
- I want other audience members to not exclude us, people who have disabilities, in concert halls.

Fourth meeting: When going shopping

◆ Some things I should be mindful of:

- Don't bring valuables or too much money with me when going out. And I should watch out for thieves and robbers.
- When I want to buy something, I should check the price of the item and consider whether I can afford to buy it. Also, I should consider whether I NEED it or I just WANT it.
- I should check my change when the shop assistant gives it to me. Also, I should not forget to take what I buy.
- I should be careful not to go close to or pass through dangerous places when going out.

◆ What kinds of support I need/want

- When I go out, I want to have some pocket money to use freely. I want my family to trust that I will take good care of myself. If I have difficulty in getting to the stores or other places I want to go, I want my family to take me.
- I want to go shopping with my friends and supporters. I need someone to help me to make an appointment with my friends and tell me where the meeting place is.
- I need there to be easy-to-understand signs in stores, and I want the stores to be easy to go in and out of without barriers. When I cannot find something I am looking for, I want shop assistants to be patient and to help me to find it with a smile. Then I need them to take the time to support me patiently in the payment/check out process.
- I want other customers not to scold and exclude us, people who have a disability.

Sixth meeting: When going to a movie

◆ Some things I should be mindful of:

- I should check where the movie theater is and how to get to there, and I should also check the time of the movie I want to see in advance.
- When entering a movie theater, the first thing I should do is check where the emergency exits are. I should be careful not to make noise or engage in any behaviors that may bother other audience members. (EX: sitting in other audience members' seats, eating foods with strong or unique smells, smoking, littering, taking photos or videos while the movie is showing, etc.)
- I should be aware of whether someone is touching my body, and whether I am touching another audience member's body.

◆ What kinds of support I need/want

- I need support to find information about movies, movie theaters, and how to get to movie theaters. If I have difficulty in getting to a movie theater, I need transportation support.
- I need the pocket money to see a movie. I need someone to help me buy the movie ticket. Also, I need someone to guide me to my seat in the movie theater.
- I want to have Easy-Read information about movies. Also, I need easy-to-understand signs and barrier-free movie theaters.
- I want to go to a movie with my friends and supporters. I want other audience members not to exclude us, people who have a disability, in the movie theaters.

Discussion and Limitation : Does the changed operation of the Network bring in new voices and lead to positive progress?

◆About the participants with ID

☐ Positive points:

- Even though the facilitators tried to lead the topic of discussion toward 'Civic Engagement', participants decided the year's topic which is much closer to their daily life. In general the outcomes seemed like common sense, in the process the participants with ID put forward their own ideas and got to think about what their own responsibilities were when doing leisure
- They described their support needs when doing leisure activities. EX: companionship and trust from family and, and also mobility support, Easy-Read signs, and information, barrier-free facilities and environments.

☐ Limitation:

- The facilitators and the participants almost only meet six times for around 36 hours in total a year, it is hard to really know whether the new voices were the participants with ID who had never talked about these things before.
- Self-Advocacy is a continuous process. However, many participants and local organizations see these gatherings as single events. There is always a fresh influx into this Network, but this may also be a cause of stagnation for those who participate continuously. .

◆About the facilitator with ID

☐ Positive points:

- The meetings before and after the discussion meeting at each event which enabled the three facilitators to exchange their opinions at greater length and more profoundly, and created an opportunity to think about how to support this person with ID as a leader in this Network.
- It was a good democratic experience to know that the leader is not the one who decides everything but has to respect others' opinions.

☐ Challenge:

- When the argument between two participants over 'whether going to a pub is a good thing' continued for over 20 minutes, the facilitator with ID didn't step in as the moderator to stop the argument because she thought she had to respect their discussion. This case provided an experience that led to a solution, and also let her know that being a leader and a self-advocator did not mean she could not ask for help.
- Even though having stress she was still willing to continue in the role of facilitator next year, and did not mind having more participants with ID join her in this role.