

Short Report

Effective Health Checkup Methods for Adults with Intellectual Disabilities Part I: Intervention to Workplace Users with Autistic Tendencies

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Abstract

This study aims to provide an intervention for effective health checkup methods to adults with intellectual disabilities (ID) combined with autistic tendencies at the workplace in the community. We sent requests for participation to ninety six users in a metropolitan area. The final subjects were four users (4.2%), males, ages ranging from 20's to 40's, and ID from moderate to severe. After the intervention, three of the participants (75.0%) were able to successfully undergo all of the medical inspections. Our research affected participants concerning opportunities for proper checkups, reducing unnecessary expenditures, and changing attitudes of people involved in this study.

Introduction

The World Health Organization (WHO) report entitled "Healthy Ageing - Adults with Intellectual Disabilities (ID)" in 2000 showed that appropriate health assessment by medical staff was one of the most important needs for people with ID all over the world [1].

According to the 2005 population census report in Japan, three fourths of people with ID were living in communities and the number of those in their 30's, the second baby-boom generation, was increasing along with the general population [2]. These statistics show that health problems of adults with ID in Japan will become more serious issues in the near future, especially in the community. Japanese government policies focus solely on early detection of abnormality in children and the employment of people with ID, and as of yet there has not been a national policy framework on health issues for adults with ID [3-5].

One of the authors found that taking a health checkup was an important opportunity for adults with ID to have contact with medical institutions in the communities. However, there were still a number of persons with ID who worked for companies or workplaces who could not take health checkups properly because of communication difficulties with medical staff [6].

We reviewed literature on health assessment [7] and found that intervention studies dealing with health checkups of adults with ID in the communities were very rare. A few studies were carried out by a research team in Australia [8]. They reported on the effects of a comprehensive health assessment programme (CHAP) using a cluster randomized trial (more than 200 subjects). The characteristics of subjects with ID in this study, however, did not specify combined autism or autistic spectrum disorder (ASD). In addition,

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the Australian government has a Medicare system similar to the Japanese one called the universal medical care insurance system that covers all of its citizens, but there is no health care checkup system for adults with ID in Australia in the same way as Japan for people with ID.

In our research, we focused on adults with ID combined with autistic tendencies who tend to have communication difficulties, which is one of the features of autism (see appendix). They have difficulties in not only communicating with medical staff but also accessibility to medical institutions [9, 10].

In Japan, there are about six thousand workplaces called '*Shoh-kibo-Sagyosho*' which provide jobs and activities for adults with (ID) in the community [11]. Most of them do not have a full time medical staff, yet, the facilities are required by management regulations to have health checkups at least once per year [12], and at other facilities, twice a year in accordance with the law [13]. We believe if we approach workplaces even in one community, the results will contribute to maintaining and promoting the health of people with ID.

Therefore, this study aimed to provide an intervention for workplace users with ID combined with autistic tendencies to be able to take proper health checkups.

Definition of Terms

Autistic tendency

In order to receive welfare services in Japan, a person needs at least one medical diagnosis. If a person has ID combined autism, he or she tends to be diagnosed with ID only, and the autism goes undiagnosed. In this study, we approached adults with ID, even though they had not been diagnosed with autism, but exhibited characteristics similar to autism. To clarify the subject properly, we use the expression "autistic tendencies" when an adult has similar actions under category A of Autistic Disorder (see appendix) which has been defined in "Diagnostic and Statistical Manual of Mental Disorders" (fourth edition text revision) (DSM-IV-TR).

Methods

1. Subjects

We have chosen an area (Area Z) which satisfied the following five conditions:

- 1) ID population ratio of the area was similar to the national average (0.5%),
- 2) The area was in a big city (the higher the general population, the higher the ID population),
- 3) The establishments of workplaces were varied (nonprofit organization (NPO), social welfare corporation, and public et al.),
- 4) There were many workplaces at which most staff, administration and users had known the first author more than 10 years (the longer to know researchers, the shorter the time to build trust in relationship with them),
- 5) People with ID lived in a dense zone (the number of the ID population / the area in square meters was the highest).

In Area Z, there were seven workplaces for adults with ID- five of them were NPOs, one was a social welfare corporation, and another one was a public workplace. The number of users of each facility ranged from eighteen to forty seven. The ages of the users ranged from teens to 70's.

Prior to the study, we interviewed the staff and administration of six of seven workplaces in Area Z to find out what kind of problems the users had while undergoing their health checkups [14]. Since one facility administrator was serving at two of the facilities, we were able to obtain information on the situation at the seventh facility in Area Z as well.

One of the seven workplaces in Area Z had already done its health checkup, so we recruited from just six of the workplaces. We sent requests for participation to ninety six users in a community of a metropolitan area, out of which eight users (8.3%) agreed to participate in our study.

2. Procedures

We first asked the administrators of the workplaces for permission to do our study. After a phone call to each facility administrator, the researcher visited each workplace one by one, and explained the purpose of this study with oral and written descriptions. Upon receiving understanding of our study from administration, the researcher asked them to distribute the materials for research cooperation to the users. Replies from the users or their guardians were sent back to the researchers directly.

3. Intervention

Before the intervention, the first author worked as a volunteer at each workplace three or more times for the purpose of becoming familiar with its users. The intervention included asking guardians and faculty members about participants, observing them during the daytime, assessing matching abilities, building trust relationships, planning supports, practicing little by little, and going along with them to health checkups.

4. Outcome measures

We compared 1) the number of tests as inconclusive and 2) matching abilities before and after intervention.

5. Ethical considerations

Ethical approval for this research was obtained from the Ethical Committee of Kawasaki University of Medical Welfare (No.203).

Results

Table 1 shows that final participants in this study were four users (4.2%) who had problems in undergoing health checkups. All of them were males, ages ranging from 20's to 40's, and ID from moderate to severe.

Four cases were excluded in the intervention process. After asking guardians about health checkups by phone, we were told two participants were able to undergo all tests required at the latest health checkup. After some discussion the mother of one subject told us her son declined to participate in this study because he had not recently been to the workplace. Another participant, who successfully underwent all the tests, later requested a hearing test because the workplace did not include that among the tests.

Before intervention

Two subjects could not properly take vision tests. One of them, who had worked for more than 10 years at the same workplace, had never been able to properly take a vision test before.

The rest of the participants could not undergo proper hearing tests even though they could answer when their names were called at workplaces. Some of the guardians said they were dissatisfied with the test results.

All workplaces in Area Z used a medical institution for their health checkups, so the medical institution had a lot of experience relating to workplace users' health checkups.

The workplace is responsible to pay for the costs for a vision test or a hearing test even if the subject

cannot communicate during the test and there are no results. All workplaces in Area Z have had similar situations.

After intervention

Three of the subjects (75.0%) succeed in undergoing all of the tests properly. One person could not have enough time to practice before the health checkup due to the impact of the Tohoku earthquake, and, as before, was unsuccessful again undergoing the hearing test. Two of the subjects could understand picture-to-chart matching, and one subject understood the hearing test procedure through experiences during the intervention.

The most difficult parts in the intervention process were to assess and ensure the right time and place for practice, to build trust in a relationship, and to create tools tailored to individual understanding.

During the intervention, the researcher was exchanging information with guardians and facility workers. Most guardians were surprised that participants could undergo health checkups properly, and were interested in our intervention. Even medical professionals of the inspection agency at the medical institution asked the researcher how to use visual aids and showed interest in them, and the researcher was glad to give them some materials.

Table 1 Subjects' backgrounds and results before and after intervention

Case	Age	Sex	ID	Inconclusive test results		Matching ability used
				Before	After	
Case 1	30's	Male	Severe	Vision test	None	Picture-to-chart matching
Case 2	30's	Male	Moderate	Vision test	None	Picture-to-chart matching
Case 3	20's	Male	Moderate	Hearing test	None	Matching through experiences
Case 4	40's	Male	Severe	Hearing test	Same	Unclear

Conclusion

1. The effects of the intervention

One of the effects of our research was that we could provide assistance to undergo a proper and thorough medical check for users. In this study, we had access to adults with ID combined with autistic tendencies in an urban area. In addition, our approach focused on adults with ID having difficulties communicating with medical professionals in all aspects of the health checkup. Unfortunately the subjects had never been provided with a chance to learn how to deal with health checkups properly and in fact, had been ignored for a long time by the majority of health professionals during their annual health checkups. This type of situation occurs not only in the region where we intervened, but also in other areas of Japan and all over the world [1, 9, 15-19].

The Second effect of this research was the cost. Before intervention, the workplace had to pay medical check fees even when results were inconclusive. It was evident, however, that just one concentrated approach to support people with special needs to take medical examinations could reduce health cost expenditures. In Japan, the School Health and Safety Law [20] stipulates that every elementary school student must take an annual health checkup paid for by the school. Therefore, if our strategy starts from

elementary school, it will reduce a huge amount of unnecessary expenditures.

The third effect was changes in attitude of facility workers, guardians, and even medical professionals of the inspection agency. They become more and more interested in the health checkups because most of them could not have imagined that our research participants would ever be able to successfully undergo the tests.

2. Future challenges

As we had difficulty recruiting subjects for our research, this study had very few participants. Lennox et al. [21] indicated that the health status of people with ID was poor, yet very little research had been done on their health needs, and that there were several barriers to performing such research. They recommend three methods as recruitment strategies: an initial strategy, an insider telephone call strategy, and an information session strategy. We considered using these strategies in the future for recruiting participants and also need to improve the intervention process by including a larger number of subjects.

In addition, we need to clarify the effect of the intervention on the participants, so they will be able to continue undergoing proper health checks in the future.

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The American Psychiatric Association's DSM-IV-TR
Diagnostic Criteria for 299.00 Autistic Disorder

A. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

- marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- failure to develop peer relationships appropriate to developmental level
- a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:

- delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- stereotyped and repetitive use of language or idiosyncratic language
- lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- apparently inflexible adherence to specific, nonfunctional routines or rituals
- stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.