

Ask For It: Development of a Health Advocacy Intervention for Adults with Intellectual Disability and Their General Practitioners

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Abstract

Two per cent of people in Australia have intellectual disability and the adults in this population often have poor health status. This poor health can be partly attributed to communication difficulties encountered by people with intellectual disability and also health professionals in consultation settings. The design and development processes of an educational intervention to improve communication between patients, general practitioners (GPs) and also advocates in a population of adults with intellectual disability are described. The design process was collaborative and involved adults with intellectual disability, GPs, parents, support workers and other professionals. It was a nine-step development process and led to the final communication tool package, the ask (advocacy skills kit) 5-year health diary and educational session. As a result of the collaborative design and development processes, this diary included qualities not found in most other medical record keeping systems: visual appeal, advice on how to be a health advocate, utility for a range of users, privacy, portability and sufficient capacity to record personal patient information which enhanced communication between doctor, patient and advocate. It is proving to be very popular. Clear implications were found for applying established criteria and incorporating the needs of users in the design of educational interventions in the intellectually disabled population. Health promotion tools aiming to improve the current poor health status of adults with intellectual disability should be developed further.

Key words: education; general practitioners; health advocacy; intellectual disability

INTRODUCTION

Two per cent of people in Australia have intellectual disability and it has been shown that the adults in this population often have poor health status (Beange et al., 1995; Wen, 1997); why this is so has not been well documented. Research into the experiences of people with intellectual disability and health care systems remains limited (Lennox et al., 2000). The small amount of literature published indicates that for this population there are a number of conditions that are either unrecognized or poorly managed. These include sensory impairments, syndrome-specific conditions, lack of medication reviews, pain, dental hygiene, epilepsy, constipation, malnutrition, obesity, health screening, mental disorders, gastro-oesophageal reflux disease, immunizations, osteoporosis, thyroid problems, undescended testes and hypogonadism (Lennox et al., 1997). Although the overall health of this population is poor, people with more severe levels of intellectual disability have particularly bad health (Beange et al., 1995). In contrast, people with mild intellectual disability have mortality rates approaching those of the general population (Patja et al., 2000). However, the extent of unrecognized or poorly managed health in this larger group with mild intellectual disability is not known.

There is also a range in ability to communicate within this population; because of the cognitive impairment, communication difficulties are common (Jacobs, 1999). Some people do have limited literacy and still manage to live and work independently. However, many people

with intellectual disability are unable to speak, and may use communication systems with symbol languages. Frequently other people cannot understand them and they cannot understand others (Cook and Lennox, 2000).

Communication can be a problem in a medical consultation for both the general practitioner (GP) and the patient (Ziviani et al., 1999). For people with all levels of intellectual disability, most medical care is received from the primary health care system via GPs. In a medical consultation, the patient (adult with intellectual disability) may speak (self-advocate) or have someone else speak on their behalf (advocate). This advocate may be a paid support worker, a family member or a friend. This third person or advocate mediates between the patient and the GP, so the relationship is a triangular one. The advocate plays an essential role in determining the efficacy of health monitoring and outcomes, since she/he effectively acts as the interpreter for the patient (Ziviani et al., 1999; Davis et al., 2001). The doctor is also part of this triangle and it is advisable to be aware of the heightened communication needs of the doctor in a consultation with a person with intellectual disability.

Good communication leads to good advocacy. Advocacy means 'to be called to stand beside' (Cross, 1996). Within the context of disability, advocacy is a contentious term. Notions of advocacy differ vastly among parents, support workers and health providers (Stone, 1999). In this study, we wanted to broaden the term to 'health advocacy', which has previously been used to indicate a process of patient empowerment in health decisions (Gillette, 1988; Wachter, 1992; Bastian, 1998). We defined 'health advocacy' as the process of engendering advocacy skills in all those involved in medical situations with people with intellectual disability, particularly the person themselves.

As nothing exists that could be used as an advocacy tool for people with intellectual disability in medical consultations, it was decided that one should be developed. First, the problem situations in health experienced by people with intellectual disability were assessed. This was done by consulting broadly. Material was then designed that was relevant to those problem situations.

Described here is the development of an educational package designed to enhance communication and advocacy between the patient (if a self-advocate) and their GP, or between the patient, their GP and the advocate. The final package consists of a 5-year diary along with a brief intervention of an advocacy educational session. The material was pre-tested to ensure its comprehensibility and relevance (Bell and Alcalay, 1997). It is expected that this package will assist in consultations with other health professionals as well as with GPs. The development of this educational package can be classified into the nine steps described below.

METHODS

The development of the educational package was a nine-step process (see Figure 1) over 12 months. This process aimed to involve groups who would ultimately be the users of the package. Initially, we relied heavily on our networks of experts within disability services for advice. Data were collected and later used to inform the steps involved in design and implementation. This was done in a number of ways and using multiple sources, as described below.

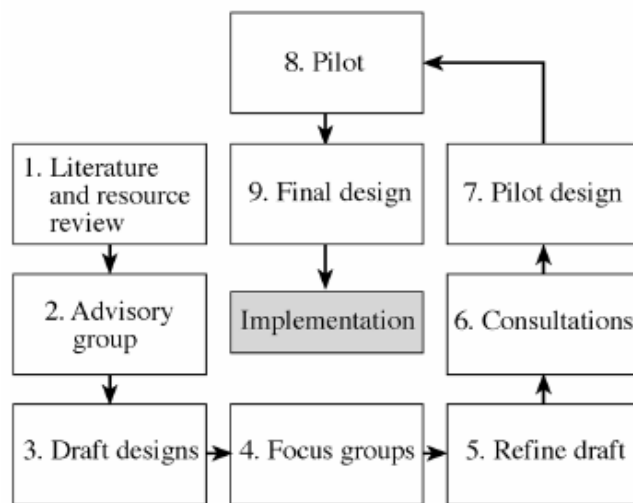


Figure 1. Intervention development process.

Step 1: review of existing resources

The study team contacted a number of people working with adults with intellectual disability to ask them what was currently being used to record health information. These people included professionals and direct support workers. A literature review of educational resource design and definitions of advocacy and health advocacy was also undertaken (Nankervis and Rebeiro, 2000). A range of criteria was developed (see Figure 2) for the development of this package for this population, and these criteria formed the basis of the evaluation (Centre for Disease Control, 1988; Center for Developmental Disability Health, 1999; Windsor et al., 2000).

Steps 2–6: consultation with advisors and focus groups

Individuals known to our study group for their expertise were invited to join an advisory group. This group of nine people met four times throughout the development process, and included two people with intellectual disability, two support workers, two parent advocates, two advocacy organization representatives and an occupational therapist. Conceptual design of the tool was refined following consultations with 21 other skilled advisors identified through our networks (see Figure 3). Graphics advice for the final draft was also sought from a professional photographer and a graphic artist.

To determine the format and content for a preferred intervention package, 15 focus groups were held with 101 people, including eight people with intellectual disability, 85 support workers, three parents, two psychologists, one GP, one volunteer friend and a sister. These focus groups were held in local neighbourhood centres, and at the most convenient times for attendees. Each focus group was asked a series of standardized questions. In order to arrive at common understandings of 'health' and 'advocacy', participants were asked their experiences of health advocacy and what steps they considered important in advocating for someone. They were also asked: how they preferred to receive information and how they thought people with intellectual disability would best receive information; what they needed to learn about improving health and about their communication with GPs; and what attributes they sought in a GP. Focus group responses were audio-recorded and transcripts were made. Two researchers independently extracted the most common themes, and refined these through consensus discussion. These themes then formed the basis of the resource design and selection of content.

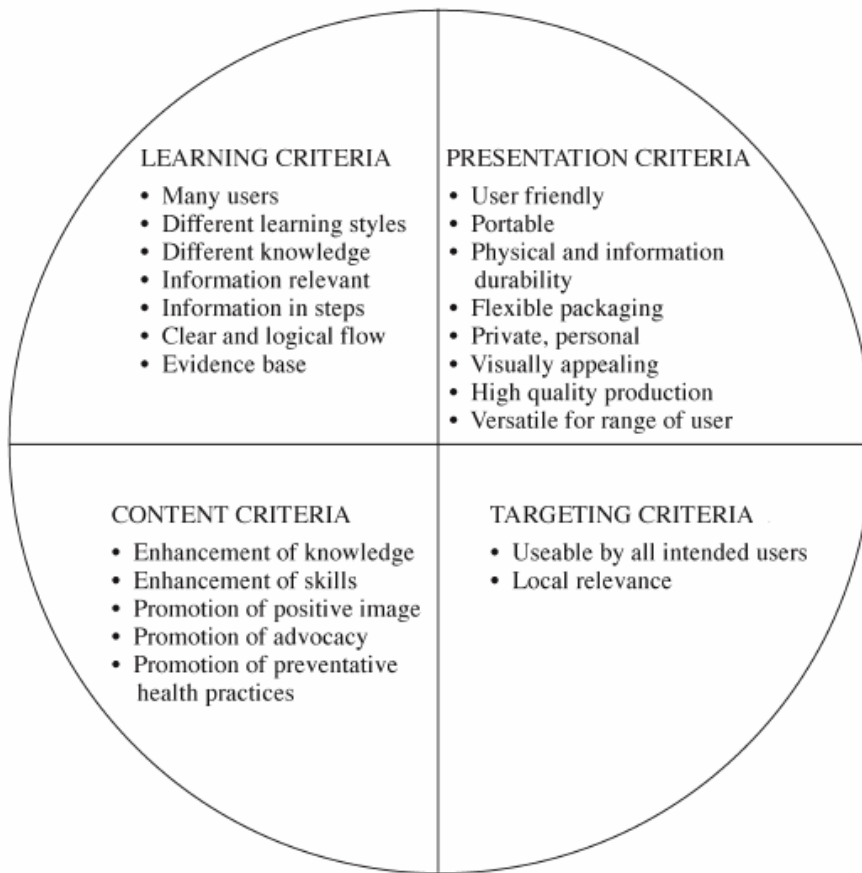


Figure 2. Criteria for tool development.

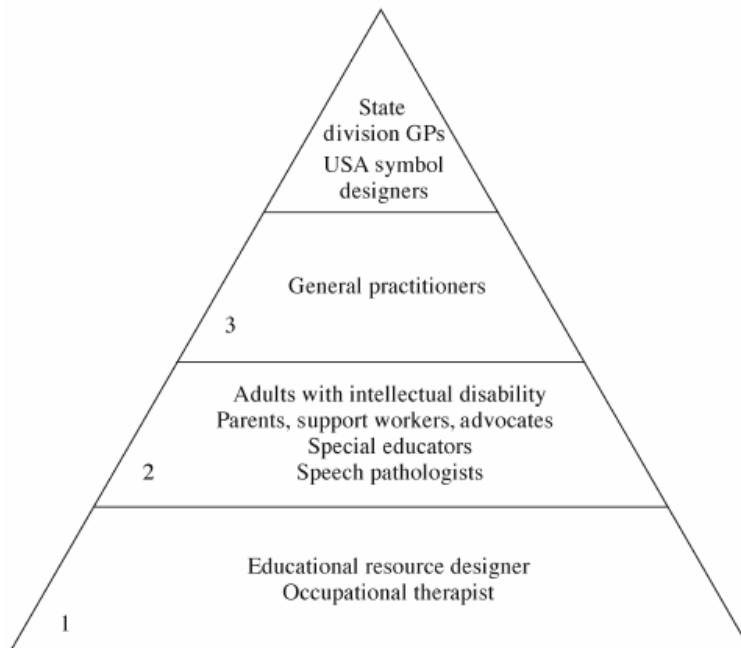


Figure 3 Skilled advisors.

Steps 7 and 8: piloting of package

The tool was designed to be used in combination with a brief intervention educational session. Brief intervention strategies have identified benefits (Miller et al., 1995; Huffey, 1997; Babor and Higgins-Biddle, 2000). The session had to provide advocacy skills for both the person with intellectual disability and the advocate by the adoption of practical advocacy principles to be used in GP consultations. The session would be delivered as a one-off education session, primarily to accommodate the participants' (people with intellectual disability, parents, support workers and GPs) limited available time. It was designed to meet a broad range of knowledge entry points, from people with limited literacy to people from professional backgrounds.

The session required active participation which, in educational terms, helps to reinforce the core ideas (Queensland Parents for People with a Disability Inc., 1983). Participants listened to the definition of advocacy, and were then led into a discussion on advocacy. An experienced mediator led these sessions. All participants were encouraged to speak, if they were willing. A handout on 'being assertive' was distributed and comments were requested. Participants were then given a diary and all sections were explained. Finally, people were asked to fill out an evaluation form of the education session.

This package was piloted with two groups: group 1 comprised 19 parents of adults with intellectual disability who use a non-government support service; and group 2 comprised seven people with intellectual disability (self-advocates) who use a non-government accommodation service. The participants for the two pilot groups were recruited via letter. Participants were invited to join information sessions in local venues at suitable times, with catered suppers. The package presented at the sessions was an educational session and the 5-year health diary to record medical consultations. Participants were told they would be contacted in 2 weeks, and were later telephoned and met in person to obtain their feedback on the package.

Step 9: final design

Throughout both the development process and the study, in response to advice, nine drafts of the diary and three drafts of the educational session were devised. They were presented to focus groups, advisory groups and people with special expertise, before the final version of the diary and educational session were available for implementation in the main trial.

RESULTS

Step 1: existing resources

When conducting background research it was discovered that daily journals, designed by disability professionals, were commonly being used in accommodation services for monitoring medical information. These journals included records of individual visits to GPs, information about patients' communication skills, and their medical history. Personal health records for people with intellectual disability, designed to be used by parents as a health monitoring tool, were publicly available for downloading from a website (Burbidge, 1999). However, we believed, as did our advisory group, that some essential elements were missing from these existing resources. These included: visual appeal, advice on how to be a health advocate, utility for a range of users, privacy, portability, and sufficient capacity to record personal patient information, which enhanced communication between doctor, patient and advocate. What the resources lacked was an overall cohesive structure along with sufficient attractiveness to motivate people with intellectual disability to use them.

The elements common to resources were: recording space for health indicators such as disease monitoring (epilepsy seizure charts); consultations with GPs and other health professionals such as psychiatrists; health checks (annual medical and dental reviews); and change monitoring (behaviour changes that may indicate illness for people who do not speak). These

common elements were used as a basis for package design, and the missing elements were then conceptualized, developed further and incorporated.

TABLE 1. Issues and solution in design

Issue	Raised by	Solution
Privacy	Advisory group Designer	Confidentiality warning Physical form
Negative view of adults with intellectual disability as patients	Advisory group Designer Speech pathologists	Personal strengths and weaknesses Likes and dislikes (e.g. waiting for doctor) Patient's communication style
Advocacy principles	Advisory group	Tips on how to be an advocate
Poor health of this population	Advisory group	For doctors, brief history of health status
Patient behaviour	Special educators Speech pathologists	Recommended use of one GP Attributes of a 'good' GP Attributes of a 'good' patient When to use and not to use a GP Active language—'I will' What to do after a consultation Symbols for symptoms like pain or dizziness (for people who use symbols to communicate), with explicit body pictures to describe symptoms
Doctor's limited time	General practitioners Designer	Section for doctor Reduced jargon Quick checklists for syndromes List of commonly missed problems Medical histories/consultation records Ways to indicate pain for patient What to take to and from a consultation for a patient Health insurance details What to tell doctor, what to record
Use by a range of people	Designer	Ring binding to enable inclusion of other records
Readability by users	Doctor Advisory group Special educators Speech pathologists	Details of statutory health attorney Current contact details for important people in patient's life Section dividers Section on patient's personal details Easy words Sections for patient use: right side of page Page numbering Limit visual distractions (especially for users with autism)

Steps 2–6: skilled advisor and focus group consultations

Table 1 briefly summarizes some of the issues raised by the skilled advisors following the focus group phase, and how these issues were resolved in the final design.

We asked participants in the focus groups how they preferred to receive information and how they thought people with intellectual disability would best receive information. The preferred medium for receiving information was overwhelmingly by video. However, a video only provides one-way communication, is expensive to produce and may rapidly become out of date. The preferred method of two-way communication was simple written material utilizing graphic illustrations. For many adults with intellectual disability, graphic symbols are used to communicate ideas. Therefore symbols were incorporated into the basic design of the tool to assist patients in describing symptoms to a doctor.

We asked focus groups what they needed to learn about improving health and their communication with GPs, and what attributes they sought in a GP. The attributes of 'good' GP included a doctor who gave more time to the patient, listened to the patient, treated the patient as a whole person, communicated primarily directly with the patient rather than the advocate, used

easy words and followed up on any medical actions. These features were incorporated into the tool design as advocacy tips for the doctor.

An issue raised by the reference group was that of privacy. When adults with intellectual disability live in shared accommodation, their homes are often used as worksites and their personal details are kept in filing cabinets in public areas. To be useful, the tool had to incorporate notions of privacy. Additional practical changes to promote its active use by people with intellectual disability were suggested by special educators, speech pathologists and the designer. As consulted potential users, the GPs suggested a section of easily accessible, readable and useable information specifically targeted at the doctor. They also requested the inclusion of information about the Enhanced Primary Care Directives. This is a national government initiative in primary health care to improve the quality of life for people with chronic and complex health needs (Royal Australian College of General Practitioners, 2000). This is particularly pertinent to this population because adults with intellectual disability may have highly complex health needs (Ziviani, 1999).

Across the consultation process, we made every attempt to incorporate all suggestions. Rarely did choices have to be made between conflicting suggestions. The final physical design of the written material was intended to support its use for recording the patient's private medical history. It was designed to deter carers from placing the diary in a service filing cabinet. It needed to have the flexibility to remove and insert materials relevant to the user, to have visual appeal, to be portable and to be durable, both physically and in terms of its content. In addition, the diary itself had to operate as a tool that encouraged advocacy from all involved in a consultation with a GP.

Steps 7–8: piloting the tool

The pilot groups determined the content and design of the final package. Parents who were participants commented favourably on the diary:

The actual diary is very useful. It is a good thing for people to have at home, and it can be used by both the person themselves and the family.

It is a good idea. The diary will help with health. It is a good idea, especially for people in respite and independent living.

Pilot group participants gave feedback in telephone interviews 2 weeks after their use of the diary. We collated and themed their comments, which were largely supportive, and made the final minor changes.

Final phase

The final package design comprised a 5-year diary entitled ask (advocacy skills kit) and a brief intervention educational session.

The ask diary (see Figure 4) was of B5 size with a sturdy Velcro-bound folder and contained 135 basic pages, with five copies of each page in the back to allow replacements without copying. It was divided into four major sections, entitled 'All about me', 'Health advocacy tips', 'For the doctor' and 'Medical records'.

The ask diary

'All about me' (39 pages) contains a record of personal details of the patient, including means of communication, previous types of residence, weekly activities, names and contact details for family members or support organizations, and contact details for health practitioners including specialists, GPs, dentists, therapists, allied health care and complementary health care. The patient, the advocate or a family member can fill in this section.

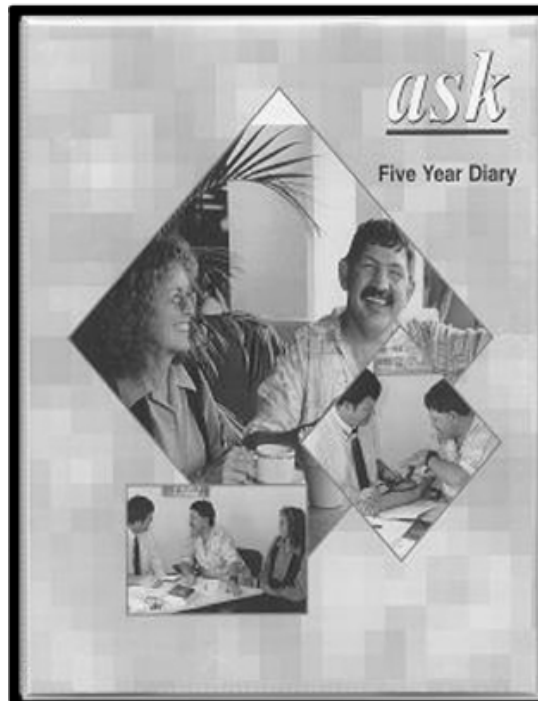


Figure 4. Illustration of the *ask* five-year diary

'Health advocacy tips' (43 pages) provides information on advocacy and how to prepare for the doctor's visits, picture symbols with line drawings of male and female bodies, and recording sheets for observations of pain, menstruation, bowel, bladder and epilepsy. The patient, the advocate or a family member can fill in this section.

'For the doctor' (21 pages) provides ideas for clinical staff on how to work with people with intellectual disability, enhanced primary care initiatives, and checklists of health problems associated with specific syndromes. The doctor uses this section.

'Medical records' (9 pages) provides records of diagnoses, operations, medications, immunizations, allergies, family history of disease and medical consultations. The patient, advocate or a family member can fill in this section.

The final section contains a description of how the diary was developed and multiple copies to cover the 5-year period, principally to save advocates' copying expenses.

The ask health advocacy educational session

The educational session was developed concurrently with the diary and was designed to accompany it. This combined package is to be used by trainers to deliver health advocacy education. In the session, advocacy principles were presented, which were accompanied by examples from within a health context. In addition, practical ideas were provided on how to actively apply the steps of advocacy, including how to negotiate and mediate, listen and record, act as an intermediary, encourage self-advocacy and how to be assertive (Kenny and Barrkman, 1999). One of the parents involved in the pilot phase commented that it 'reinforced for me the idea that doctors have certain responsibilities, and that patients have responsibilities too'.

The ask educational session plan was divided into three parts. Section one is for the trainer, with background, purpose, expected outcomes, preparation for the session and what will be needed. Section two contains guidelines for delivering the session, including an opening, definitions of advocacy, advocacy tips, how to introduce the diary, and evaluation of the session. Section three contains participant worksheets on advocacy, health advocacy, how to be assertive, how to advocate and a session evaluation sheet.

The session incorporated opportunities for participants to use their own experiences of health advocacy as content. The diary reinforced the knowledge, attitudes and skills delivered in the session (Dennis, 2000).

The education sessions were delivered by one facilitator in 50-min sessions to small groups of nominated advocates. Each participant had worksheets, a copy of the diary and an evaluation sheet to record their comments anonymously. The sessions were complemented by catered lunches.

DISCUSSION

The aim of this paper was to describe the development of an education package to improve communication in a health consultation, in particular with a GP. At commencement, the specific nature of the package had not been determined. To achieve our aim, an educational package (a diary and an educational session) was developed by extensive consultation and collaboration, in particular with people with intellectual disability and their care providers. We found that such a process could result in the development of an educational package that has the potential to improve advocacy and communication in a health consultation.

Preliminary findings show that the package has been enthusiastically received. Some comments from advocates, when asked what they liked about the diary, included: 'Everything' (the most common answer), 'All of it—it is brilliant' and 'The ability to have a written account of John when I'm no longer able to look after him'. Two-thirds of the advocates interviewed indicated that the diary had helped them to be better advocates and half of them said that their relationship with their GP had improved as a result of the information session. It was also commented by doctors that the diary would be useful with other groups, such as people with mental disorders. It was mentioned that 'It is excellent and has enormous possibility for (other) client groups'.

We feel that the positive comments reflect a population of people with intellectual disability and carers who are desperate for attention to be paid to their needs; the comments also suggests substantial face validity. Frequent requests for the diary are received from both within Australia and beyond, as it has become more widely known among service providers and researchers.

As adults with intellectual disability are often accompanied by their advocates to consultations with health professionals, we found that the package had to meet the needs of a broad range of users. There was a wide divergence in ages, ability and education levels in participants, advocates and health professionals. Advocates comprised a wide range of people and included parents, siblings, cousins, residential workers, volunteer friends and service managers. Consequently, the package content and presentation had to account for such diversity, and hence be designed in a generic format. We don't believe the generic nature of the package diminished its acceptability to adults with intellectual disability and their advocates. Indeed, once the diary is completed with the personal details of the individual, this person gains a greater sense of ownership as it not only belongs to them but also describes aspects of their life. Adults with intellectual disability often do not experience a sense of control over their lives or ownership of

documentation, which is about them. Our experience and that of others in this field is that adults with intellectual disability welcome this shift in emphasis (Stone, 1999).

The absence of accessible and attractive health advocacy tools for this population is surprising given their poor health. In fact, in one sense it is remarkable that such a tool hasn't been developed in the past. However, those interested in improving their health care have largely neglected the community care of this population, as the focus of concern has been on marginalization and poor health care in large institutions (Lennox et al., 2000). This recent move to community care and increasing interest in the health of this population through the development of state government-supported university centres has been fundamental to the development of this package.

It is not known yet whether the package does improve the advocacy and health of people with intellectual disability. This tool is currently being evaluated in a randomized controlled trial in South East Queensland, Australia. The results of the trial will be published as they become available. It does seem likely, however, that such a package will improve the current poor health status of adults with intellectual disability.

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