Integrated care for intellectual disability and multiple sclerosis
Jansen, Danielle

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Chapter 3

Towards improving medical care for people with intellectual disability living in the community: possibilities of integrated care

Daniëlle EMC Jansen, Boudien Krol, Johan W Groothoff, Doeke Post
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Abstract

Background: The ongoing deinstitutionalization results in several problems in medical care delivery to people with ID, such as an increased workload for GPs and a lack of active coordination and cooperation between health care professionals. A major consequence is the incidence of untreated, yet treatable medical conditions. An opening for better coping with these inconveniences may be found in a coordinated integrated care approach. The aim of this paper is to show the significance of integrated care for people with ID and to present an overview of recent integrated care initiatives.

Method: a literature search about integrated care among people with ID is conducted in order to trace relevant literature between 1995 and 2003.

Results: although integrated care appears to offer potentials for eliminating the fragmentation and discontinuity in the medical care for people with ID and for reducing the workload for GPs, only few studies focusing on integrated care for people with ID are evaluated and actually published.

Conclusions: even though the advantages of integrated care are theoretically well known, the precise applicability of this approach on people with ID has still to be confirmed.
Introduction

Until recently, medical care for persons with intellectual disability (ID) in the Netherlands was only for a minor part the responsibility of the General Practitioner (GP). In 1995 about three-quarters of the estimated population of 120,000 people with ID were GP-registered. However, due to the increasing deinstitutionalization, a further 10,000 institutionalized persons with ID will move to private homes and group homes in the community in the next decade, and therefore have to turn to a GP instead of an institution doctor.

Literature shows that the delivery of medical care to community living people with ID differs from medical care for the general population mainly on two aspects, namely population specific aspects and discipline specific aspects. Population specific aspects in the first place include a higher prevalence of certain (complex) medical problems. Compared to the general population, people with ID show a higher prevalence rate of both mental disorders and physical disorders like epilepsy, sensory loss, skin disorders and (increased risk of) fractures. Certain psychiatric and physical illnesses are difficult to detect and diagnose in people with ID, among other things because of the atypical presentation. Secondly, people with ID often experience several chronic disorders and handicaps at the same time, which complicates the treatment process. Thirdly, communication difficulties of the patient with ID is mentioned as a barrier for the delivery of adequate medical care. For people with ID it is difficult to describe their symptoms or give the answers their GP needs for adequate management. They sometimes may not understand what the doctor is doing and may not cooperate in diagnostics and comply with the treatment. A change in the normal day-to-day behaviour may be the only indication that a person is experiencing discomfort. In such cases, the behavioural disturbance may be perceived as the primary problem by carers and doctors, while the underlying medical disorder is ignored.

In addition to population specific aspects that complicate the delivery of medical care to persons with ID living in the community, discipline specific aspects are also likely to cause problems in the provision of medical care. The shift from institution doctor to GP gives cause to the question whether a GP has sufficient knowledge about the specialized medical care for a person with ID. As a matter of fact, people with ID are mainly used to living in institutions which requires no or minimal involvement of a GP for medical treatment. As a result, medical problems of persons with ID and the specific requirements for communicating with them, are not part of the educational program for GPs. GPs are therefore often ill-informed about the different aetiology of certain disorders and unfamiliar with diagnosing and treating the person with ID. Secondly, a lack of active coordination and cooperation between health care professionals and limitations in consultation time are two frequently mentioned barriers in the delivery of medical care for people with ID. Due to the aforementioned population specific aspects, people with ID need more of the GPs' time than the average patient.
In conclusion it can be said that the delivery of medical care for people with ID is complex and that GPs are equipped insufficient in order to provide high-quality medical care for people with ID. A number of authors frequently pays attention to the (consequences of) these inconveniences in the provision of medical care for people with ID.\textsuperscript{4,5,9,10} In general, Lennox & Kerr state that, in case a community-based population of people with ID receiving primary care were to be examined, one was likely to uncover three main findings: (1) untreated, yet treatable, simple medical conditions, like hearing impairments, vision impairments, pain or infections, gastrointestinal problems, refractive errors, epilepsy, bronchitis, hernias, psychiatric disorders, skin disorders, obesity, hypertension, heart disorders and thyroid disorders, (2) untreated specific health issues related to the individual’s disability, and (3) a lack of uptake of generic health promotion, such as blood pressure screening.\textsuperscript{4,5,9,10}

Aspects of care on which one has to focus in order to anticipate the pressure on primary health care for this vulnerable part of the population are cooperation and agreement between GPs and other health care professionals and continuity of care. Continuity of care refers to the organised, coordinated and steady passage of individuals through the various elements in a system of care and services.\textsuperscript{11} In this respect, a coordinated integrated care approach may be an answer. Integrated care, which emerged in the United States in the 1990s, is the integration of health care, social care and related services.\textsuperscript{12}

Integrated care is described by Mur-Veeman \textit{et al.} as ‘(inter-sectoral) cooperation (coordination/networking) between care providers from both the health (medical) and social care sector in order to deliver seamless/continuous care to (vulnerable/elderly) people with multiple needs, as a remedy to fragmentation and discontinuity’.\textsuperscript{13} It is required when the services of separate agencies and individual professionals do not cover all the demands of the multiple problem service users. Goals of integrated care are to improve quality of care and quality of life, consumer satisfaction, and system efficiency for patients with complex problems cutting across multiple sectors and providers.\textsuperscript{14}

The first aim of this study is to explore the value of integrated care for persons with ID. The second goal is to present an overview of the literature on integrated care initiatives in this field. The overview will be presented in the second part of this paper.

\textbf{Methods}

In order to explore the value of integrated care for people with ID, the outcome variables are explored that may benefit from health care based on the principle of integrated care. For this purpose (and with reference to the goals of integrated care), relevant databases (Medline, Embase and Cinahl) are searched on the keywords ‘intellectual disability’ or ‘mental retardation’ and ‘integrated care’, ‘continuity of care’, ‘satisfaction’, ‘efficient health care’ and ‘effective health care’. Subsequently, per outcome variable the way in which integrated care contributes to enhancing quality of health care to people with ID will be addressed.
In order to deal with the second part of this paper, exploring recent initiatives in integrated care for people with ID, a review is performed. The focus of the review is on international literature published between 1995 and 2003. The reason for choosing this period lies in policy development with respect to the care for people with ID. From halfway through the nineties policy-makers have concentrated on community care concepts such as socialization and autonomy. As a result, health care for people with ID has become part of the general health care increasingly.

Since the first search on the keywords ‘integrated’ and ‘integrated care’ provided unsatisfactory results, the search was expanded with other related keywords such as ‘multidisciplinary’, ‘multidisciplinary care’, ‘shared care’ and ‘disease management’. These concepts are also used to describe certain care arrangements. The concept of integrated care however is more comprehensive and can be seen as an umbrella term for all its variations in practice.15

The value of integrated care for community-living people with ID

As mentioned before, deinstitutionalization brings along several changes in medical care delivery. One way to anticipate the changed circumstances in the provision of medical care may be a coordinated integrated care approach. Concerning integrated care, the provision of medical care by a coordinated team of professionals always has been assumed to be valuable.16 Integration should occur across time and health care settings, including primary health care, specialist care, and inpatient care.17 An interdisciplinary approach is needed for comprehensive assessment, treatment, and management in order to be successful in accomplishing the following goals;17,18

1. reduction of fragmentation and discontinuities in medical care;
2. improvement of patient satisfaction and outcome;
3. supply of efficient and effective medical care.

The above mentioned goals that guide the selection of disorders to be ‘managed’ by the principles of integrated care will be specified in order to explore the value of integrated care for people with ID.

The most important motivation to make use of integrated care is the presence of fragmentation and discontinuity of health care. As with health care for the chronically ill, continuity of care is of major importance for people with ID. Health care for chronic problems particularly requires an integrated approach from multiple perspectives. Each level of the health care system involved should cooperate and share in the joint goal of optimal care. Care has to be planned over the course of the disorder, follow-up visits should be scheduled and organisations have to act proactive in the care for the chronically ill part of the population. Allowing symptoms or the onset of preventable complications to prompt patients to seek help is costly, inefficient and ineffective. By contrast, planned care permits the early detection of complications and the quick identifications of decline in
patients’ health status. Little information is available with respect to fragmentation and discontinuity of care in persons with ID. In this respect Lennox et al. listed GPs’ perceptions of the barriers and solutions in providing medical care to people with ID. A number of GPs mentioned the poor continuity of care with ID-patients, particularly as a result of carers seeking out the help of numerous doctors. In a more recent study 44% of general practice registrars indicated that they did not provide good continuity of care, while two-thirds of the respondents found it easier to establish ongoing doctor-patient relationships with non-disabled patients than with their disabled counterparts. The short duration of the registrars’ attachment to a particular practice may contribute to difficulties with continuity of care. However, time restrictions, barriers in communication with patients and carers, and uncertainties about patients’ baseline behaviour are also likely to be factors that constrain an ongoing therapeutic relationship. Although information about fragmentation and discontinuity in health care for persons with ID is scarce, it is likely that many problems in the care to this population (e.g. passing over underlying causes of medical problems, lack of knowledge and experience in professionals and unfamiliarity of professionals with potentials of colleagues and inadequate referrals) can be attributed to the delivery of low-quality care (e.g. fragmentation and discontinuity). Provision of high-quality care will not be achieved unless all parties included - people with ID and their families, carers, primary health care, and specialist services - use a proactive approach. Integration of all these individuals, their roles and their services will facilitate the provision of high-quality primary care.

A second beneficial effect of integrated care is the improvement of patient satisfaction and outcome. Similar to the scarce information about continuity of care for people with ID, studies on the satisfaction of care to (community-living) people with ID are limited. As far as we have been able to determine, no studies on this subject are available. As far as improvement of outcome is concerned, reduction of impairments and resulting limitations in activities are two important outcome targets with reference to ID. Impairments such as motor- and sensory impairments, epilepsy and speech defects are frequently present in people with ID. Possible ensuing limitations in activities include communication problems and reduced mobility. With reference to the evaluation of care for people with ID the two concepts ‘morbidity’ and ‘mortality’ are also elementary. Since there are numerous medical disorders associated with undiagnosed or poorly managed ID, people with ID still have a significantly higher mortality rate. Complications of drug interactions as well can be mentioned as an outcome variable, since multiple-drug regimens are common in people with ID because of the coexistence of medical and psychiatric disorders.

A third reason for management of ID according to the principles of integrated care is the high costs of a chronic disease, the high volume or/and high costs per patient, the high prevalence of the disease and high indirect costs due to work loss. With reference to the costs of ID it can be said that in the Netherlands mental retardation is the greatest single cause of health care costs in men (10.3% of the total costs of health care for men). Additionally, in future these costs are expected to rise even more because of the ageing
population. Because of a continuously growing patient population that has been pressuring (the costs of) health care for decades, governments face a pressing demand for efficiency in the management of chronic conditions and other expensive disorders like ID. However, instead of integrated, population-based care that emphasises patients’ needs, policies and plans often promote models of acute, episodic care, which result in fragmentation and waste to the system. Integrated care may be a challenge in order to make significant gains. Health care organisations have to streamline services, upgrade the skills of health care workers, focus on prevention, and establish information tracking systems to provide planned health care for predictable complications.\(^{17}\)

From the aforementioned it turns out that the provision of medical care for community living persons with ID leaves much to be desired. Although little information is available about continuity of care and patient satisfaction, it may be assumed that many medical problems of community living people with ID are the result of inefficient and low-quality healthcare delivery.

**Recent initiatives in integrated care for people with ID**

Table 1 lists the studies that describe integrated care services. For each study, the table shows the initiative, the authors, the year of publication, the kind of study and any possible effects of the integrated care initiative. Four publications on integrated care initiatives were found. The overall aim of the services is to provide comprehensive services to individuals with ID and their families.

The Interdisciplinary Team Approach of Lubetsky et al. provides a comprehensive assessment of the child, family, and community resources.\(^{27}\) The results of the assessment are presented to the parents and the interdisciplinary team works with them to compile a prioritized list of treatment recommendations. According to the authors, the family-centred consultation model allows the parents to determine the degree of involvement of the professionals, make informed decisions, formulate a treatment plan with the assistance of the professionals, and plan a more flexible and comprehensive program.

The multidisciplinary clinic for individuals with Down syndrome described by Lovell & Saul is designed to serve as a resource both physicians and families.\(^{28}\) The clinic provides comprehensive medical evaluation and preventive medical screening, along with initial and follow-up developmental assessments.

Green et al. describe the development of an integrated multidisciplinary service with good multi-agency links.\(^{29}\) The service consists, among others, of a child clinical psychologist, a community nurse, an occupational therapist and a consultant child and family psychiatrist. The multidisciplinary team offers support to other professionals such as health visitors and pediatrician. Weekly meetings are held in which the team discusses developments, supervision and current issues.

The independent advisory team illustrated by Van Berckelaer-Onnes et al. consists of a pool of professionals who have experience with individuals with ID who exhibit challenging
behaviour. Parents, institutions, schools and others can turn to this team if they are concerned about the treatment of their child, client or pupil. The advisory team can summon the aid of various professionals, e.g. psychiatrists, psychologists, special pedagogues and/or speech pathologists.

In order to explore the value of the described integrated care initiatives, we looked whether the papers did contain evidence on the effectiveness of the initiative. The conclusion is that only one study includes an evaluation: Green et al. included an audit of the service eight months after it was started. The results of this audit show a reduction of the waiting-list from one year to three months and a decrease of amount of out of country referrals and residential placements. However, nothing is mentioned about patient satisfaction or effects of the integrated care initiative on health status of the person with ID.
Table 1 Effectiveness of integrated care for people with ID

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Quality of evidence</th>
<th>Effectiveness</th>
<th>Cost-effectiveness</th>
<th>Patient satisfaction</th>
<th>Satisfaction healthcare providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-Centered / Interdisciplinary Team Approach(^{27})</td>
<td>Case study</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
</tr>
<tr>
<td>Down Syndrome Clinic(^{28})</td>
<td>Descriptive</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
<td>Not evaluated</td>
</tr>
</tbody>
</table>
| Child and adolescent health service for children with learning disabilities\(^{29}\) | Audit after eight months | - Reduction of waiting-list from one year to three months  
- Decrease of amount of out of country referrals and residential placements | Not evaluated       | Not evaluated         | Not evaluated                     |
| Independent regional advisory teams\(^{30}\)                            | Case study          | Not evaluated                                                                 | Not evaluated       | Not evaluated         | Not evaluated                     |
Discussion

In theory integrated care appears to offer potentials for eliminating the fragmentation and discontinuity in the health care of community living people with ID; it may bring along several advantages like improved continuity, effectiveness and efficiency of health care. However, this assumption has been difficult to prove empirically, in the first place as a result of the unclear distinction between the different concepts that describe forms of cooperation between several health care workers e.g. shared care, multidisciplinary care, integrated care and disease management. Clear definitions of the various concepts are lacking and also possible differences are ambiguous. As a result, concepts are used mixed up, without knowing whether it is applied in the right way. In this study, also other concepts are used (e.g. multidisciplinary care) in order to retrieve collaboration initiatives between the cure and care sector. Besides the use of different concepts in which integrated care appears, the design and delivery of integrated care in itself often differs per country and depends on the system’s structure (governing and organisational structures), differences in finance and the variation of providers and services involved.31

A second reason why the effectiveness of integrated care initiatives is been difficult to prove empirically is the lack of evaluation studies. This review shows that only one integrated care initiative has been evaluated, taking into account that the evidence of the evaluation is weak. Similar outcomes (few empirical studies on the effectiveness of integrated care) are presented in recent studies on the effectiveness of jointly provided health and social services for other target groups. In this respect, Glendinning mentions a study of Cameron et al. who conducted a systematic review of research into the effectiveness of jointly provided health and social services. They identified only four studies which met the reviews’ inclusion criteria and even these failed to provide conclusive evidence of the benefits for users of joint working.18,31 Also Rosendal et al. conducted a study to gain more insight in the effectiveness of health care delivery, provided on the basis of cooperation and coordination between generalists and specialists.12 However the concept referred to is related with the concept integrated care, the so-called transmural care is less comprehensive than integrated care since it generally does not include the whole care-process of patients. The conclusion of the authors is that at the time of the study relatively little has been published in the Netherlands with respect to the effectiveness of transmural care. The available evidence is not very strong due to the small number of studies published and the poor quality of the study designs. Vondeling also concludes that, although it is generally assumed that integrated care results in increased effectiveness and quality of care while being cost-effective or even cost-saving at the same time, systematic evaluation, including an evaluation of the relative costs and benefits of these arrangements, has largely been lacking.15 Reasons for the lack of evaluations are, among other things, the complexity of the intervention and the perceived methodological difficulties.
Consequently, even though in writing the advantages of integrated care are well known, the precise applicability for community living people with ID still has to be identified. The fact is that people with ID can be distinguished from people with, for example, chronic illnesses by the nature of the disorder. ID is not considered as an isolated disease but as a complex of symptoms. Most integrated care initiatives have a disease-specific approach that may disrupt the continuity of care toward individual patients with multiple disorders. Taking part in several multidisciplinary programs is often accompanied by insufficient attention for co-morbidity and interactions between the different treatments resulting in diminishing coordination of care. Therefore care should not only be integrated across time and health care settings, but also across all categories of chronic conditions moving beyond traditional disease boundaries.

Despite the few integrated care initiatives, there seems to be a tendency toward involvement of more professionals in the health care of persons with ID living outside an institution. The need for connecting different health professionals increases, both within a certain sector and between different sectors. Following this, a rather unique project on integrated care for community living persons with ID has been started in the Netherlands. Within the primary health care area of a circumscribed region, several networks are being established in order to provide integrated care. The model of care is directed towards GPs and specialists, who, with reference to certain medical problems, are not able to make a diagnosis or treat a patient with ID adequately. In case of difficulties in understanding and obtaining information from the patient or due to a lack of knowledge of conditions or illnesses common in people with ID, it is possible to consult a physician specialised in health care for persons with ID working in one of the networks. The specialised physician decides whether the person with ID has to be referred to another professional within the network or if an advice from the ID-specialist will suffice. All professionals and organisations that commit themselves to the network are experienced in providing health care for persons with ID.

When the person with ID is seen by a number of professionals, a multidisciplinary advice is formulated that will be presented to the referring GP or specialist. When local expertise to act on the advice is present the regular health care professionals will follow the (multidisciplinary) treatment advice. If not, the treatment will consequently be started by the professionals of the network. When the treatment is completed, the patient is referred back to the GP or regular specialist. With this initiative, several professionals, organisations and a health insurance company try to improve medical care for community living persons with ID by means of providing the right care at the right moment by the right person.

The project will be evaluated in order to determine whether it generates beneficial effects for persons with ID and for GPs. Outcome variables will be quality of care for persons with ID (among other things better continuity of care, detection of undiagnosed health problems and patient (and family) satisfaction), the degree of relief of the GPs and the satisfaction of professionals concerned. The implementation process will be evaluated as well; barriers in implementing the network will be one of the subjects of study.
References


