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THE VIEWS OF FAMILY CAREGIVERS ON THE DEINSTITUTIONALISATION OF PSYHIATRIC CARE IN RUSSIA

As with many other countries, the Russian Government has declared its intention to deinstitutionalise mental health care and provide people with mental disabilities with services that go beyond inpatient care, thus offering better prospects for integration into society. These policies have major effects not only on the lives of the people with mental disabilities but also on informal caregivers such as parents and spouses, who care for diagnosed children and partners. This study explores the views of family caregivers on the deinstitutionalisation of psychiatric care in Russia. The study is based on interpretive policy analysis. Qualitative interviews were conducted with twenty caregivers in a large Russian city. The results revealed that there was very limited support among caregivers for the reforms. They did not question the practice of institutionalised care or treatment in stand-alone psychiatric clinics, but rather took this for granted. Highlighting negative social attitudes towards the people with mental disabilities, carers claimed that stand-alone psychiatric services provide a protective environment away from the hostile outside world. Caregivers lacked knowledge about any particular social approach to mental disability or alternative ways of organising the mental healthcare system. Besides this, the caregivers were strongly disturbed by the prospect they may lose the support they receive from existing services. Although the carers criticised the current situation in psychiatric hospitals, they claimed that hospitalisation provided them with significant respite from care. All interviewees reported being overburdened, complaining of insufficient financial and social support. We suggest that caregivers in Russia have good reason to be suspicious of the reforms, which in many cases are not accompanied

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by proper funding, or by the development of alternative services or activities
to prevent stigmatisation.

Deinstitutionalisation is a topical issue in international mental health
policy. It can be defined as the replacement of large and centralised psychiatric
institutions by smaller, less isolated community-based alternatives for the care
of people with mental disabilities (WHO 2003a). This policy also suggests in-
tegration of mental health services into general health facilities to reduce the
stigma associated with seeking help from stand-alone psychiatric services
(Ibid). The major arguments for deinstitutionalisation are that it protects hu-
man rights, increases the quality of life of individuals with mental illness, and
prevents their isolation and stigmatisation. These aims emerged first in the UK
and USA in the mid-1950s, and subsequently in continental Europe and Scan-
dinavia. The reforms gradually led to the closing or downsizing of psychiatric
hospitals and the development of community-based services in many countries
(Novella 2008). These ideas were later introduced into Central and Eastern
Europe (Becker, Vázquez-Barquero 2001).

As part of the major political and social transformations that followed the
collapse of the Soviet Union, reforms of the mental health care system have
been initiated in the Russian Federation (RF), whose healthcare system was
earlier sharply criticised for its political abuse, restrictions of patient rights and
over-institutionalisation (Jenkins et al. 2007). The basis for a Post-Soviet men-
tal health policy was formulated in 1992 in the law 'On Psychiatric Care and
Guarantees of Citizens' Rights in its Provision' (Supreme Soviet 1992). This
document proposed new principles in line with international standards in pro-
tecting patient rights. Thereafter, several specific bills, orders, and pro-
grammes were approved to regulate the scope and quality of mental health
services in accordance with this basic provision (Shek et al. 2011). The policy
documents called for the integration of mental health services into general
health services to help overcome the social exclusion of patients (McDaid et al.
2006). The most recent federal mental health programme (MoH 2007) called
for the decentralisation of psychiatric care, a reduction in hospitalisation peri-
ods, a decrease in the number of repeated hospitalisations, and the develop-
ment of outpatient services. This policy programme reflects the international
trend towards the deinstitutionalisation of psychiatric care (Litvinova 2010).

The process of deinstitutionalisation has led to the changes in the social or-
ganization of care for people with mental disability. It underlines the importance
of collaboration between the healthcare system, social welfare services and fami-
lies, all of whom jointly take responsibility for care. In many countries deinstitu-
tionalisation reforms have not been accompanied by the sufficient provision of

community-based services that would offer social support to people with mental disabilities (WHO 2003a; Petrea 2012). A similar tendency can be observed in Russia where there is a lack of social services provision and economic support for caregivers (Gurovich 2012). The current care allowance is only 1,200 roubles (20 EUR) per month (Presidential Decree 2014). Furthermore, only caregivers who have no other income (such as a salary or pension) qualify for it. This means that caregiving is not considered a paid job, and many carers suffer financial difficulties. The process of deinstitutionalisation without the development of sufficient alternative services increases the burden on family caregivers (Blomgren Mannerheim et al. 2016). Caregivers thus face a higher risk of serious role distress and consequently a low quality of life (Quah 2014). Therefore, family caregivers are considered to be an important group affected by the burden caring imposes. This article aims to shed light on how family caregivers perceive reforms aimed at the deinstitutionalisation of psychiatric care in Russia. Caregiving is viewed as a set of activities involved in meeting the physical and emotional requirements of dependent people in the normative, economic and social contexts within which the care is assigned and carried out (Daly, Lewis 2000). It requires material, physical, intellectual and emotional resources.

A number of studies have shown that families of people with mental disabilities have expressed their opposition to the closing of hospitals (Heller et al. 1988; Larson, Lakin 1991; Tabatabainia 2003). This is due to uncertainty over how people with mental disabilities and their carers will be affected by deinstitutionalisation (Tossebro 1996). They pointed to the inadequacy of available community-based settings and the provision of good services by existing institutions (Tabatabainia 2003). Caregivers were also concerned about the negative effects of premature discharge from hospital (Brand 2001) and the challenging behaviour of their relatives with mental disabilities (Sherman 1988). A European survey that was conducted with family caregivers from nine West European countries (Brand 2001) revealed that families often feel abandoned as a result of deinstitutionalisation reforms, as they are left without sufficient information or support services. However, in those cases when sufficient non-institutional services were provided, strong initial opposition to closure of hospitals was converted to support for the new services (Conroy 1985; Heller et al. 1988).

Russian researchers (Levina, Ljubov 2009; Limankin 2016) have also revealed resistance to reforms on the part of carers. They found that caregivers do not support the development of new types of service, demanding instead better funding for existing services. Oleg Limankin (2013) points to a lack of attention to the views of family caregivers in Russia, explaining this as a result of the dominance of a paternalistic approach in Russian psychiatric care. According to this line of thinking, officials and professionals responsible for organising health care are not interested in the viewpoints of patients and their relatives and, therefore, fail to take them into account. According to the WHO (2003b), however, the personal experiences of family caregivers offer valuable insights, which

should be considered when designing and developing services. Therefore, in this study we are interested in learning how informal caregivers, who in most cases are spouses and parents of persons with mental disabilities, evaluate existing inpatient and outpatient mental health services in Russia. We are also interested in what they think needs to be done to restructure and improve these services and whether they support reform on the basis of deinstitutionalisation.

The context of caregiving in Russia

Although 46,500 psychiatric beds have been cut across Russia since the 1990s (almost a quarter of the total national bed capacity), the Russian mental healthcare system is still largely based on institutional care (Kotsjubinsky et al. 2013). The number of psychiatric beds is 109.53 per 100,000 (WHO 2011), which is higher than the European median of 39.4 per 100,000 of the population (Petrea 2012). A substantial proportion of patients (22 per cent) stay in hospital for more than a year, and a significant number for up to five years (Gurovich 2012). As Isaak Gurovich (2012) notes, the reduction in the number of hospital beds was not followed by the development of new alternative forms of care that could have compensated for the reduction of institutional, inpatient care. Alongside psychiatric hospitals, another type of care institution in Russia is the *internats*, psychoneurological inpatient facilities that are large institutions (often containing more than 500 beds), in which people with mental disabilities generally remain for life (Krivoshei 2001). Lonela Petrea (2012) claims that the old Soviet practice of hiding people deemed disabled translates nowadays into the practice of relocating them from mental health hospitals to *internats*.

The mental health service system in Russia is also characterised by a widely developed network of outpatient clinics, known as *dispansers*. These services are typically a person's first point of contact with the mental healthcare system. Although these are outpatient services, they do not meet the criteria of well-organised community based care (Bartenev 2005). According to the WHO (2003a) the key features in assessing community based care are the accessibility of services and success in reducing the level of stigma associated with mental disorders. In most Russian regions, *dispansers* cover large areas and large numbers of people, a fact that does not seem to support the goal of greater accessibility. In large Russian cities, a *dispanser* may be responsible for populations over 1 million people. Additionally, visiting a dispanser carries a lot of stigma with it due to the Soviet stigmatised practice of *uchet* (registration), whereby patients are listed on a psychiatric case register (Kotsjubinsky et al. 2013). In actuality, these *dispansers* appear far closer to the WHO definition of institutions that deliver stand-alone mental health services functioning in isolation from communities and lacking strong links with the rest of the healthcare system (Ibid).

According to the WHO (2003a), community mental health services can also be provided by local community members without professional training.

The associations of service users and their carers, as well as other non-governmental organisations, can advocate for patient rights, and offer family caregivers emotional and practical support. In Russia, such associations are undeveloped (Limankin 2016). The concept of community, a cornerstone of modern mental health services at the Western countries involving self-organization and mutual support of caregivers, is at best shaky, if not lost in Post-Soviet countries (Petrea 2012). Furthermore, current governmental policy in Russia is not favourable to NGOs. In 2006 the Government passed a law significantly expanding control over NGOs and restricting their right to privacy (Kamhi 2006). Then, a 2012 Law was passed tightening control on NGOs funded from abroad (Dufalla 2014).

Methodological Approach and Research Materials

The methodology of this study is based on an interpretive policy analysis (Yanow 2000), which focuses on the meanings that policies have for a broad range of the policy-relevant public. In this analytical framework, the notion of policy, instead of being primarily viewed in legislative document or state rhetoric, is understood by referring to the multiple interpretations of policy-relevant groups. Sharing thought, speech, practice and their meanings, policy-relevant groups are defined as interpretive communities (Ibid). Policy analysts working with interpretive methodology study how representatives of interpretive communities construct their realities, as well as define policy problems and their solutions (Sheikh, Porter 2010). This approach focuses on understanding values, feelings, or beliefs that interpretive communities express in discussing policy problems (Yanow 2000). Dvora Yanow (2000) argues that at least three such communities operate in any policy situation: policymakers, implementing agencies, and affected citizens. In our study, family caregivers are viewed as an interpretative community with its own opinions on how to conduct mental healthcare reform. Interpretive policy analysis is derived from a constructionist approach in social research (Sheikh, Porter 2010). From this perspective, the term mental disability is a socially relative category subject to dispute, the precise boundaries and meanings of which vary according to time and place (Busfield 2001). Therefore, the caregiver discourse on mental disability and the development of mental health services is viewed as socially constructed and tied to the political, social and cultural contexts of a particular society.

The participants of this study were recruited at a mental health outpatient clinic (*dispanser*) in a large Russian city. In order to ensure the anonymity of our interviewees, the city's name is not revealed in this article. Access to the field was based on previous research collaboration with the *dispanser's* staff. The first author (Olga Shek) had the opportunity to interview family caregivers at the *dispanser* when accompanying their relatives with disabilities. Several participants were additionally recruited using the snowball method, which entailed interviewed family caregivers assisting the researcher in identifying other potential respondents.

Research participants were chosen in accordance with the definition of family caregivers used in previous studies (Quah 2014; Perlick et al. 2008) according to the following criteria: (1) they were immediate family members of the care recipient, (2) they supported the care recipient financially, (3) they were the most frequent collaborators in treatment, and (4) they served as the main contact in case of emergency. In total, twenty semi-structured interviews were conducted in 2014–2015 with family caregivers of adults with mental disabilities. Most interviewees were mothers aged between 40 and 73 (17 interviews). The interviewees also included one sister (aged 30), one father (aged 53) and one grandfather (aged 65). All participants consented to be interviewed and for their anonymous data to be used for analysis.

We asked the caregivers how they viewed existing mental health services, both inpatient and outpatient, and how the services should be improved. The question guide also covered aspects of mental health policy such as the downsizing of hospitals, the reduction in the number and length of hospitalisations, the integration of psychiatric services into general healthcare, and the development of community-based services. At the start of the interview, the interviewer introduced herself as a researcher from a Finnish university. It seemed that this encouraged some interviewees to speak about deinstitutionalisation with reference to Western countries.

We recognise that our study has certain limitations typical of qualitative studies, such as the small sample size and the fact that all the interviewees came from one big city in Russia with relatively good access to mental health services. It might be that the opinions of caregivers from other Russian regions or rural areas would be different. The chosen city tends to play an important role in leading innovation programs nationally, which was the reason why we were interested if the new mental health policy ideas were supported there.

The data was analysed using thematic analysis. Three key themes emerged in the arguments of carers: (1) the current policy of deinstitutionalization is unclear; (2) their attitudes to hospitals are ambivalent; (3) stand-alone psychiatric services are seen to provide a protective environment for people with mental disabilities and their carers away from the hostile outside world.

An Unclear Policy of Deinstitutionalisation

The interviewed caregivers lacked knowledge about the ideas behind deinstitutionalisation and how these reforms were being implemented in Russia. Some of them had heard about deinstitutionalisation in Western countries, however their knowledge about it was quite vague. For example, one of them said: '*I read that there [in Western countries] a person could always decide if he wanted to take medicine or not, could decide whether to live or not. I do not agree with this*' (woman, age 61). Another, expressing her negative attitudes towards deinstitutionalisation, said:

> I have extremely negative attitudes to those who give out leaflets with things written on them like 'If your relative had a bad experience in psychiatric services, you should complain'. There is a global trend to leave people alone, not to treat patients, to close hospitals. I do not know what their final aim is. But of course there are many problems in our hospitals (woman, age over 40).

Although this woman complained about hospitals, she was not eager to support the initiatives, addressed to criticise psychiatric care, which she viewed as a set of organised attacks. She suggested that '*somebody must be paying these people*' to argue against psychiatric care. She was suspicious about such activity, associating it with an anti-psychiatric movement, deinstitutionalisation. The woman thought that this '*global trend*' leads to an absence of treatment. One plausible reason for her negative interpretation of these activities is the effect of broader processes in Russian society, such state policy promoting suspicious attitudes to NGOs, especially to those funded from abroad. She was concerned that the reforms would further damage a previously stable and powerful psychiatric system, bringing uncertainly and risks.

Although the caregivers had negative views about NGOs criticising psychiatric care, they supported actions against the state authorities, such as signing a petition, when proposed by mental health professionals. One of the interviewed mothers remembered how she was frightened by the possible closure of the hospital: '*When I was told that the hospital would be closed, I thought that's it, it will be the end for all the patients*' (woman, age 73). She was also proud to say that she had signed a petition put forward by mental health professionals against the closure of the hospital, and that the hospital still operated. In this case, participation in 'activism' had resulted in a victory against the system. The caregivers and professionals built a coalition against state authorities whose perceived aim was to dismantle the system (see, also Shek, Pietilä 2016).

In some cases caregivers felt it was inappropriate to complain about psychiatric care. A father of a man with mental disability explained his acceptance of his son's illness, the hospital's problems as well as his passive attitudes to the reforms by reference to the religious sentiment of humble acceptance:

> There is question here, 'do I deserve this kind of treatment or not?' I have done a lot of bad things in my life. <…> I do not think that my opinion is important. I don't think about this [reform], I take it as it is. <…> Do you remember the film 'The Heart of a Dog'? In this film, somebody said that as soon as the cleaners find their way into government then everything would fall apart (man, aged 53).

This father aligned the relatives of people mental with disability with cleaners, who, as he thought, should not be involved in the decision-making process about psychiatric reforms, suggesting only professionals could decide how the system should be organised.

'The Hospital is Bad, but We Need It'

Although the carers criticised the current situation in psychiatric hospitals, they nevertheless argued against downsizing them. They voiced a shared concern about poor material conditions and rude nursing staff. One of the mothers described the hospital in the following way:

> There are 20, 30, 40 patients in a ward here. Somebody wheezes, somebody snores, somebody sings. All this has an effect on them. But the staff has very bad attitudes towards patients. I saw myself that they treated them badly: they called them bad names, abused them and shouted. All this is a big minus. <…> However, I was satisfied with hospitalisation, the treatment was good. I am very satisfied that she [daughter] was in the hospital for two months. She left the hospital as a person, an absolutely normal, healthy person (Woman, age over 50).

The excerpt demonstrates that our interviewees had ambivalent attitudes towards hospitals. The decision to hospitalise a relative was often described by interviewees as a difficult one due to the bad conditions there and simultaneous need for help. They also recognised that hospitalisation provided them with some respite from care. The respondents pointed to their own tiredness and the lack of any financial or social support from the state. Most interviewees were mothers. This fact illustrates the phenomena of feminisation of care practice, when women are assigned a role of caregivers and show a readiness to do this job without payment (Zdravomyslova, Temkina 2015). Several caregivers reported that they had changed their jobs to part-time, less-qualified and lower-paid work in order to have enough time to care for their relative. They, therefore, were a subject to what has been termed a 'care penalty'; this represents the idea that carers make sacrifices when performing care work, such as loss of personal time or job opportunities (Ibid). Many of our respondents were close to retirement age or retired. Because of their own age they found it increasingly difficult to care for their relatives. However, a lack of support to family caregivers is typical not only of Russia; international studies also point out that public policy often views the work of informal caregivers as a personal, moral obligation, and not as an extension of the workforce (Levine et al. 2010).

The carers acknowledged that the 'unacceptable' or aggressive behaviour of relatives could be difficult for themselves and those around them. One of the mothers, recalling the hospitalisation of her son, said:

> The hospital has disciplined him. He had a feeling of licence: if I want to, I can break a window. This feeling of licence is a rather dangerous tendency. So he ended up in the hospital. He realised that there were bars on the windows, there was no outdoor activity. Because of this he understood that there is a thing such as restraint. This feeling of licence started to disappear (woman, age 51).

From this mother's perspective, frightening conditions in the hospital had an unintended positive effect, serving as a punishment for 'bad' behaviour and

disciplining her son. She said that after hospitalisation she disciplined her son by reminding him about the hospital. Another mother (age 47) also confirmed that after a five-month hospitalisation her daughter became more responsible. She explained this not in terms of any positive results of the treatment, but rather in terms of the daughter's fear of being hospitalised in such a 'terrible' hospital again.

A mother whose daughter had remained continuously in a psychiatric hospital for the past six years said that her daughter was very bored there. She complained that the psychiatrist did not permit her even to take her daughter to the church nearby the hospital. She tried to improve her life in the hospital by making informal payments to hospital staff:

> Unfortunately, I have no money to encourage the hospital staff. I give them a little bit so that they will look after my daughter. At one point she was sleeping on the bed frame because she suffered from bed-wetting and did not want to wear a nappy. Then we started to buy our own mattress and blankets for the hospital. I give a little bit to the staff, cigarettes, 100 roubles, cheese or something too. Then they change her gowns, because they get absolutely ragged (woman, age over 40).

Despite her criticisms of the hospital, she concluded: '*I need the hospital very much, because I'm not able to cope with my daughter at home*.' When she was asked why her daughter had stayed in the hospital for so long, she answered that the daughter was '*really ill*' and there were no alternative services for such people. From the carers' point of view, the only existing alternative to hospital was the *internat*. Their opinions about *internats* were extremely negative. One of the mothers said: '*Internat is the end of everything, they do not receive any treatment there. They [internat staff] say honestly that in six months they [patients] will die*' (woman, age 71).

The carers were pessimistic about their relatives' lives after they were no longer able to care for them. However, one of the mothers (woman, age 64) knew of a positive example. She spoke about a sports club for young people with disability that simultaneously provided an opportunity for carers to meet each other. She described how the club members had helped a young man with mental disability to live in his own room after his mother's death. However, such examples of independent living and mutual help between caregivers are an exception rather than a common practice.

Protective Environment in Stand-alone Psychiatric Services

When discussing existing outpatient services, the caregivers complained about poor material conditions, long queues, or occasionally negative attitudes from the staff. However interviewees tended to have more positive views of *dispanser* (stand-alone psychiatric outpatient clinics) compared to district policlinic (outpatient clinics that provide general and specialist care for both people

with mental illness and 'mentally healthy' people). Several respondents claimed that policlinic staff were less attentive than those working in dispansers: '*There is an old regime in the dispanser, they phone and ask about a patient's health, while the policlinic care less*' (woman, age 73). By 'old regime' she was referring to the Soviet period. Although this practice was reminiscent of the Soviet *uchet*, she thought that such attitudes were better than the indifference she encountered in general healthcare. Taking into account the social isolation of caregivers, it seems that carers understand the notion of 'being supported' as connected to those cases when somebody other than themselves is interested in the well-being of their relatives. One of the mothers complained about the absence of proper care for her son in the policlinic:

> Doctors in policlinic are afraid of such patients. They send them to psychiatric care. I asked for a health certificate for summer camp for my son. It was not about mental health, but just about physical health. The doctor gave me such a look. She didn't give me the certificate (woman, age 53).

The interviewees also thought that general practitioners in policlinic did not have negative attitudes, but simply had less time for each patient because they were overwhelmed with paperwork. The carers also experienced negative attitudes from visitors of a policlinic. And, on the contrary, as one of the respondents pointed, there is a 'special atmosphere' in the *dispanser*. Describing the shabby old *dispanser* building, she said that she felt she had gone back to the 'Brezhnev era'. While such an association might be deemed a criticism, she also suggested that the *dispanser* environment, along with the staff's caring attitudes towards caregivers, created a 'calming atmosphere':

> I like it that they see the problem here, they look into the soul of a person. I want to say that they spend time. It was very difficult for me. <…> I feel better here. Then we started to meet mothers. The *dispanser* is like a second home for me (woman, age 46).

As was mentioned above, the carers often complained of social isolation. They said that in a dispanser they had an opportunity to meet other carers and discuss shared problems with them. Several caregivers reported that most of what they had learned about mental disability and the types of service available had been gathered from communication with other carers.

The caregivers noted that the day hospital (a part of the *dispanser*) provides an opportunity for people with mental disability to communicate with each other. One of the mothers said: '*There are children who attend it for many years. Attending the day hospital serves as a means of communication for our children <...>, they make friends there*' (woman, age over 50). To justify the necessity of special services for the people with mental disability she explained that her daughter was discharged from local rehabilitation centre because of her 'inappropriate' behaviour. This demonstrates that people with

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mental disability are sometimes excluded even by the organisations aimed to help people with any kind of disability. The respondents thought that their relatives had significant difficulties in communicating with 'mentally healthy' people and needed a 'protective' environment provided by stand-alone psychiatric services. They also claimed that sometimes 'mentally healthy' people had difficulties in communicating with those with mental disability because of the latter's aggressive or improper behaviour. Although most relatives pointed to the usefulness of special segregated services, a couple of the mothers said that they had tried to find other organisations that worked with 'mentally healthy' and 'ill' people together. One of the mothers (woman, age 63) claimed that for her son it was much better to communicate with healthy people because he learned new social skills. However, she recognised that such people should be specially prepared to accept her son's occasionally unusual behaviour.

Conclusion

This study has revealed that the interviewed caregivers were very reserved in their support for the deinstitutionalisation and concerned about the possibility of losing the support from existing services. The respondents were overwhelmed by their caring responsibilities, and the hospital provided them with at least some respite. While international studies have demonstrated how the carers in the Western countries have opposed deinstitutionalisation due to satisfaction with existing inpatient services (Tabatabainia 2003), our respondents simultaneously argued for preserving the hospitals while also criticising them. They were trying to adapt to the exiting mental healthcare system and even found some positive sides in its deficiencies, such as the frightening conditions in hospitals that were perceived as a helpful disciplinary measure. This system was seen by caregivers as non-ideal, but something already known and stable while deinstitutionalisation reforms were associated with uncertainty and the risk of losing even the minimum support they get now. However, these concerns may well reflect an objective shortcoming of the reforms. As was mentioned above, the decrease in the number of beds in psychiatric hospitals has not been accompanied by the development of alternative services.

Stress among carers is increased by the social isolation and stigmatisation of families of people with mental disability. The caregivers claimed that standalone psychiatric services provided a protective environment away from a hostile outside world. The *dispanser* was a place where people with mental disability could communicate between each other and caregivers get support from staff and their peers. Discussing their relative's mental disability as a medical pathology that should be treated by special psychiatric services, the majority of caregivers considered such segregation to be normal. They lacked knowledge about alternative ways of organising the mental healthcare system. Information about the social approach to mental disability would help them in

understanding the meaning and significance of the reforms for the social integration of people with mental disabilities. The interviewed caregivers felt more like observers than potential participants of reforms. We suggest that the engagement of caregivers in research might increase their awareness. And finally, we need to underline that the provision of sufficient economic and social support to caregivers is an essential factor in changing their suspicious attitudes towards the reforms and important precondition for their readiness and ability to participate in measures to improve the delivery of services.

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