Quest

Newsletter

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Fixing the Health and Disability Systems for ME and FM

The National ME/FM Action Network was contacted recently by someone relatively new to Myalgic Encephalomyelitis and Fibromyalgia asking how to advocate on behalf of the ME/FM community here in Canada. We wish we had an easy answer. We have been trying for decades. We are very proud of our efforts and what we have achieved. But we are also dismayed by the lack of response from government.

Hopefully, there will be breakthroughs soon so that the next generation won't have to fight the same battles that our generation has been fighting. Unfortunately that may not happen. So this newsletter focuses on what we have learned and what we visualize as next steps.

The history of ME and FM can be summarized very briefly. The health system adopted the myth that ME and FM were not real or serious health conditions. Therefore, front-line health care was not needed, health research was not needed, and disability supports were provided grudgingly if at all. The international ME/FM community has overturned the myth, but the health and disability systems here in Canada have not responded. This has left the ME/FM community under-served and in great need. There has been a lack of response in other countries as well, but that is no excuse for what is happening in Canada.

You can read more about the history of ME and FM and of the contributions the National ME/FM Action Network has made in Quest 137 (2023), the 30th anniversary issue of our newsletter.

Contents

Fixing the Health and Disability Systems for ME and FM 1

Constitutional Responsibilities 2

Health and Disability at the Federal Level 3

The Convention on the Rights of Persons with Disabilities 4

Our UN Submission 6

CRPD Review and Follow-up 7

The Implementation Gap 8

The Quality of Life Framework 8

Is This a Good Time to Move Forward? 10

Additional Notes 11

In this issue, we refer to various issues of our newsletter Quest. To find them on-line, go to *https://mefmaction.com/index.php/resources/quest-newsletters*

We use a number of abbreviations in this newsletter including:

ME = Myalgic Encephalomyelitis

FM = Fibromyalgia

CHRC = Canadian Human Rights Commission

CRPD = Convention on the Rights of Persons with Disabilities

ESDC = Employment and Social Development Canada, a federal department

ODI = Office for Disability Issues, part of ESDC

PMO = Prime Minister's Office

Constitutional Responsibilities

We have to start with some constitutional law because it tells us who in Canada is responsible for what. Canada is a federation. Canada's formal constitution assigns some responsibilities to the federal government and some responsibilities to provincial governments. There are also constitutional rules that need to be considered in matters when territorial and indigenous governments are involved.

Responsibility for the delivery of health care and education is assigned to the provinces. There are, however, nuances. The federal government can try to influence the provinces using techniques like money transfers and persuasion. The federal government has some roles in health care such as monitoring and research. It is also responsible for health care delivery in some special cases, such as on indigenous reserves and for the military.

Responsibility for income support is divided. The federal government is responsible for targeted programs like Employment Insurance, Old Age Security, the Canada Pension Plan and, most recently, the Canada Disability Benefit. The provinces have general responsibility for welfare and disability payments.

Responsibility for issues like employment equity is also divided. For employment equity, the federal government can make rules for the federal government and federally regulated businesses, while provinces can make rules for provincial governments and provincially regulated businesses.

The National ME/FM Action Network generally focuses on federal government issues but remains aware that provincial issues need to be addressed as well. We are also aware that there are other players who are not within government that need to be involved such as health organizations and school boards.

Health and Disability at the Federal Level

In 1993, Prime Minister Kim Campbell split the federal Department of National Health and Welfare into two separate entities: 1) Health Canada and 2) Human Resources and Labour Canada. This restructuring separated federal health programs from federal social welfare and labour programs. Human Resources and Labour Canada is now called Employment and Social Development Canada, or ESDC for short. ESDC has an "Office for Disability Issues", or ODI for short.

The split happened at a time when Medicare was evolving and the federal government was becoming more involved in health care funding across the country. We surmise that the old Department wanted to focus on core health issues and wanted to shed responsibilities like administering social programs and dealing with matters that were more community-based than health-system-related. Those would be matters like finding housing, finding employment opportunities, developing community programs and encouraging the accessibility of buildings and transportation systems. The primary clients for these services were seen as people with vision loss, hearing loss, mobility issues and intellectual issues. This became the core disability community. People with recognized chronic illnesses like diabetes and cancer continued to be served through the health system. ME and FM did not have a home in either the health or disability system.

ME and FM should have been recognized as disabling all along, but especially when Canada ratified the Convention on the Rights of Persons with Disabilities because the CRPD bases disability around reduced participation in society, not on diagnoses or symptoms. However, nothing really changed. A former-director general of ODI, sticking to the old status quo and ignoring the CRPD, told us a few years ago that ME and FM would be recognized as disabling when the traditional disability community decided to accept them.

We would be happy to work with the traditional disability community. However, we have repeatedly found that the traditional disability community, which has worked together for a long time, simply assumes that the ME/FM community has the same issues that they do. There are times when the ME/FM perspective differs from the perspective of the traditional disability community. This is partly because ME and FM have different impacts on people than the other health conditions do and partly because ME and FM have not been incorporated into the health and social systems so there is a lot of catching up to do.

Meanwhile, we are getting mixed messages from ODI on whether its mandate covers all disabilities or only the traditional ones. Here are four examples:

- ODI has been given responsibility for the content of the Canadian Survey on Disability and has added some non-traditional categories to the survey but has not grappled with the findings for them.
- ODI was given responsibility for proposing a Canada Disability Act, but narrowed that down to the Accessible Canada Act that targets traditional issues.
- ODI commissioned work on modernizing the concept of disability but only the traditional community was consulted.
- ODI has been assigned responsibility for implementing the Convention on the Rights of Persons with Disability at least at the federal level, but hasn't clarified whether or not it sees ME and FM as being in scope.

The Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities is a key document in disability issues. The CRPD was ratified by Canada, which means that Canada said that it agrees to follow its principles. Canada, in this case, means the federal government, the provinces and the territories who all supported the ratification. That hopefully means that they will work individually and collectively to fulfill the CRPD principles.

In the CRPD, health and disability are intertwined. According to the CRPD "*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others*".

This description of disability relies heavily on the International Classification of Functioning, Disability and Health (ICF) which was developed by the World Health Organization. Impairments (symptoms) are caused by health conditions, and problems occurs when these symptoms affect the activities people can do which then affects their participation in society.

For a very practical application of the ICF, see our Canada Pension Plan-Disability Application and Appeals Guide, chapter 4 and Appendix 1. The appendix contains worksheets, one for symptoms (impairments), one for activities that could be limited, and one for capabilities needed to participate in the workplace. One can trace from the illnesses one has to the symptoms to their impact on activities to, in this case, their impact on employment.

https://mefmaction.com/docs/CPPGuide.pdf

The CRPD calls on governments to address barriers they can address. It must be recognized that government cannot solve all problems. Here are several scenarios:

- For people with ME and/or FM, impairments can affect their ability to participate in the workforce. A barrier to working might be a lack of flexibility around working conditions. Government can call upon employers to make accommodations for employees.
- But, in some circumstances, dropping out of the workplace is a better option than continuing to work. Not being employed can lead to lack of employment income and that can seriously affect overall participation in society. Lack of income is a barrier that government can address by ensuring that there are income support programs in place.
- People with ME and FM can have difficulty accessing income support programs which require a doctor's note because it can be hard to find medical support. Lack of medical support is a barrier government can address, or it can change the requirement for a doctor's note.
- ME and FM affect the quantity of activity people can do, not necessarily the type of activity people can do. Some income support programs like the Disability Tax Credit are designed around specific types of activity limitations. Program criteria is a barrier that governments can address.
- With reduced energy, young people with ME and/or FM may have difficulty attending school full time, or even getting to school at all. Education is an important way for young people to participate in society. Governments can ensure that there are alternatives to full-time and in-person attendance.

The CRPD identifies a number of topics governments should consider (health care, education, voting, etc).

Then the CRPD turns to the issues of collecting and using statistics (article 31) and national implementation and monitoring (article 33). In particular, article 33 states:

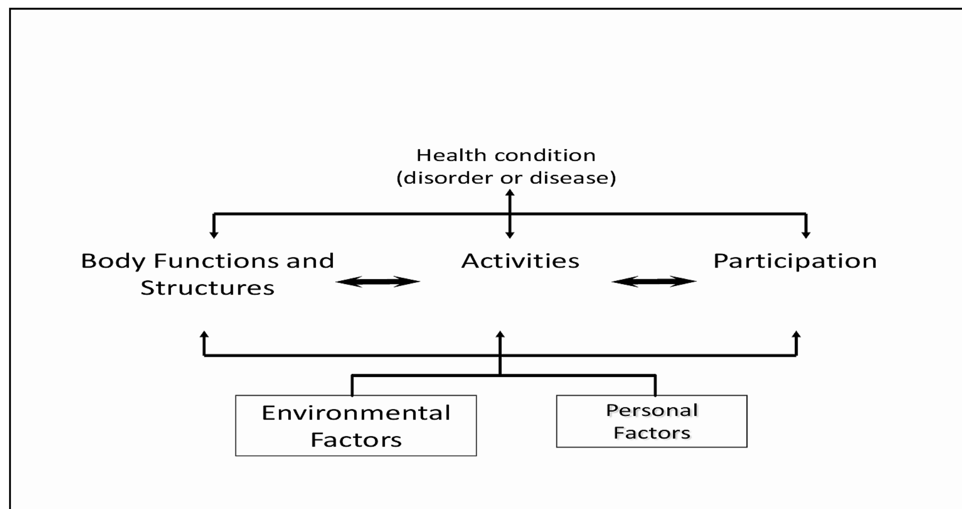
States Parties...shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

States Parties shall...maintain, strengthen, designate or establish within the State Party, a framework...to promote, protect and monitor implementation of the present Convention.

Implementation means that people across departments and levels of government identify what needs to be done and do it. As focal points, the federal government designated the Minister of Foreign Affairs for international issues, the Minister of Justice for legal issues, the Minister of Canadian Heritage to raise awareness of rights and to coordinate government reporting on the CRPD, and ODI to be the federal government's focal point to coordinate disability policy across the federal government and to consult with the disability community. Canadian Heritage is also supposed to chair a Continuing Committee of Officials on Human Rights bringing together federal, provincial and territorial governments. Whether provincial and territorial focal points have been appointed is not clear.

Monitoring means watching whether the implementers are doing what needs to be done and sharing the observations with the public. The Canadian Human Rights Commission was appointed the federal focal point in the 2019 Accessible Canada Act.

As for the role of the disability community, the CRPD says that "*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations".*When it comes to monitoring, the CRPD says that "*Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process". A* key message is that the disability community should be involved, but government is ultimately responsible.



Our UN Submission

When Canada ratified the CRPD in 2010, it agreed that Canada's performance would be reviewed by a UN committee from time to time. The first review took place in 2017. The second review (technically the combined second and third review) culminated in a hearing that took place Geneva in March 2025 and in a report that followed a few weeks later.

The National ME/FM Action Network contributed to a group report that was submitted to the hearing. We also made an individual submission which you can find in English and French in Quest 144 (2024).We were looking for projects that would make a difference for the ME/FM community, could be done over the next several years, would build a stronger understanding of ME/FM disability issues in government and would set the stage for further initiatives. We assumed that the next review would be around 5 years away. However, it now appears that the UN will again combine reviews, and the combined 4th and 5th review will not take place until the mid 2030's.

Item 1 in our CRPD submission is **public service literacy**. The public service needs to recognize that health and disability are intertwined, that health and disability need more attention, and that the CRPD covers chronic disabling medical conditions like ME and FM.

Item 2 in our CRPD submission is **health care**. In a January 2026 email to the Minister of Health, we pointed out very specific things that could be done to help ME and FM immediately – posting current information about ME and FM on the federal government website, updating and publishing current statistics on ME and FM, confronting the inequities in government funding of research, and looking at the interface between health and disability issues. These activities have value on their own, but also build a foundation for broader discussions on health care delivery. The broader discussions are going to be complex, involving provinces, territories and medical associations. Fortunately, there is a lot of good material about ME and FM available, ranging from clinical guidelines to government action plans, including a task force report that was submittedto the Minister of Health of Ontario in 2019 and has been gathering dust ever since. *https://www.ontario.ca/page/final-report-task-force-environmental-health*

Item 3 in our CRPD submission is **statistics**. CRPD article 31 calls on governments to collect and use information. We identified four aspects: reviewing survey content, publishing the results, actually using the results, and messaging the meaning of disability. Work could start with the publication of recent statistics on ME and FM (see previous paragraph) - the data has already been collected through recent rounds of the Canadian Community Health Survey. We have demonstrated the kinds of tables that tell stories that government should be interested in. It is now a case of putting together tables for recent years. Then government should look at the tables and consider their implications. Another aspect is reviewing the findings of the Canadian Survey on Disability. The findings of the CSD should guide government programs, but there are considerable discrepancies. Notably, chronic pain is the most common disability type under the CSD but receives little disability attention, and most CSD disabilities are classified as dynamic (rather than continuous) disabilities but receive little disability attention.

Item 4 in our CRPD submission is **reviewing the Disability Tax Credit program**. People with ME and/or FM have difficulty qualifying because the eligibility criteria were developed without the ME/FM form of impairment in mind, and because people have difficulty finding health professionals to complete the form. The same critical review could be applied to other income support programs.

Item 5 in our CRPD submission is **special education Ontario**. Part-time and homebound schooling are rarely thought of as special education options but they should be. What is learned in the Ontario review could be used in other school systems.

In retrospect, we could have added another item – i**ncreasing access to legal support**. This became apparent with a study we published in Quest 148 (2026), which described the skepticism that ME applicants face when applying to income support programs

CRPD Review and Follow-up

It is interesting to see who in government attended the March 2025 UN CRPD hearing in Geneva and who did not attend. The two chief delegates for Canada were high level public servants from ESDC and Global Affairs Canada. Additional federal government delegates came from ESDC and Global Affairs, plus the departments of Canadian Heritage; Indigenous Services; Statistics Canada; Justice; and Immigration, Refugees and Citizenship. There were also delegates from Saskatchewan, Manitoba and Quebec. The Canadian Human Rights Commission attended in its role as monitor. Notably, there was no delegate representing Finance even though the department of Finance is responsible for the very important Disability Tax Credit program, and there was no delegate representing health, possibly because Canada wants to pretend that health is separate from disability. There were no delegates from other provinces and territories. The hearing was a political exercise, not an operational one. The final report was also a political document.

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We made our submission in November 2024, well in advance of the UN hearing, hoping that the federal government would build something into its departmental plans for the 2025-26 fiscal year. That did not happen.

Hoping to see something in the 2026-27 plans, we contacted the Minister of Health and the Minister responsible for ODI. These emails were shown in Quest 148 (2026). Departmental plans for 2026-7 were released on March 13, 2026 and ME and FM have been left out again.

https://www.canada.ca/en/treasury-board-secretariat/services/planned-government-spending/reports-plans-priorities/2026-27-departmental-plans.html

**

In February 2026, eleven months after the UN hearing and report, we were invited by ODI to an on-line meeting of disability organizations. Over a hundred people were on-line, mostly representatives from traditional disability organizations. The Director-General of ODI hosted the meeting. She asked attendees to state their priorities. We emphasized the seriousness of ME/FM issues and the importance of sorting out responsibilities. There was no discussion around any of the issues put forward during the meeting.

There were two major take-aways from the meeting.

Firstly, the Director-General identified ODI as the designated federal focal point for CRPD implementation. However, we still don't know whether ME and FM are considered to be within ODI's scope. And we don't know if being the federal focal point gives ODI any authority to ask other federal and provincial departments to make changes.

Secondly, someone spoke on behalf of 17 traditional disability organizations and put forward their five priorities: affordability; employment; housing; repeal of Track 2 MAID (where death is not imminent); and being consulted on all issues. We are sympathetic to their requests. We have found, however, that our perspectives do differ, especially around employment (where they are looking at getting people into the workforce and we are often looking at people leaving the workforce) and Track 2 MAID (where we have heard from some people who appreciate having the option available). We also note that the list does not include key issues encountered by the ME/FM community like gaps in the Disability Tax Credit criteria, in health care services and in special education. That is why hearing from all voices is important.

As of May 22nd, we have not received any follow-up from this meeting.

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A different meeting was held in late March. The Canadian Human Rights Commission had been given responsibility for monitoring the federal government's implementation of the CRPD and they were asking groups what they should be looking for. We attended, along with around 40 other people. Much of the meeting was about pet projects, but at times it got to a more theoretical level and that is when the meeting became very interesting.

In ratifying the CRPD, Canada (the federal, provincial and territorial governments) were agreeing to implement CRPD principles. Are they making good progress? People did not seem to think so and pointed to a report written in 2023 on the "implementation gap".

The Implementation Gap

The author identified five key reasons for delays in implementation of a range of human rights agreements including the CRPD:

- responsibilities are divided between levels of government,
- courts may not recognize international obligations until they are written into domestic law,
- responsibilities are divided within each level of government,
- governments resist outside pressure around economic, social and cultural rights, and
- the roles of indigenous and municipal governments are often overlooked. (We would add other players as well such as health authorities and school boards.)

https://centre.irpp.org/wp-content/uploads/sites/3/2023/05/Closing-the-Implementation-Gap-Federalism-and-Respect-for-International-Human-Rights-in-Canada.pdf

Note that these are all complexities which make good excuses for inaction but can be overcome with will and skill.

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We then discovered a 2025 report which looked deeper into the this gap in implementing human rights agreements. It talked about:

- insufficient political will,
- chronic under-resourcing,
- poor human rights literacy within government, and
- an overall lack of incentives to treat implementation as a serious policy imperative.

It refers to these points as "deep structural deficits". The report focused on the need to put in place robust "national mechanisms for implementation, reporting and follow-up" following ratification of human rights conventions.

https://maytree.com/wp-content/uploads/strengthening_CA_implementation_reporting_follow-up_international_HR_commitments.pdf

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We also discovered a book released in November 2025 entitled A New Blueprint for Government: Reshaping Power, the PMO, and the Public Service. Written by two former senior public servants, it made the following points:

- Canada is seriously underperforming its potential,
- The federal government is a significant contributor to this underperformance,
- Political parties lack a compelling vision of how to tackle the major structural problems as well as the confidence to do it,
- Canada needs a clear roadmap and leadership to move forward.

The Quality of Life Framework

Starting with the 2025-26 planning cycle, departments and agencies are expected to talk about how their plans are going to improve the quality of life for Canadians. The "Quality of Life Framework for Canada" identifies specific measures such as Unmet needs for health care, Unmet needs for home care, Sense of belonging to the local community, Poverty, Food insecurity and Employment. We have already produced statistical evidence that the ME/FM community scores badly on those measures and that there are a substantial number of Canadians affected. That should signal the importance of looking at ME/FM issues. See Quest 112 (2017) and the supporting tables.

https://www.statcan.gc.ca/hub-carrefour/quality-life-qualite-vie/infosheet-infofiche-eng.htm

Infosheet: Quality of Life Framework for Canada

Central indicators

- ★ Life satisfaction
- ★ Sense of meaning and purpose
- ★ Future outlook

Prosperity

Income and growth
- ★ Household income
- Gross domestic product (GDP) per capita
- Productivity
- Access to high-speed Internet
- Household wealth
- Investment in in-house research and development
- General government net financial liabilities-to-gross domestic product (GDP) ratio
- Firm dynamism

Employment and job quality
- ★ Employment
- Labour underutilization
- Wages
- Job security and gig work
- Job satisfaction

Skills and opportunity
- ★ Youth not in employment, education or training (NEET)
- Early learning and child care
- Child skills
- Adolescent skills
- Adult skills
- Postsecondary attainment

Economic security and deprivation
- ★ Core housing need
- ★ Acceptable housing
- ★ Poverty
- Protection from income shocks
- ★ Making ends meet
- Homelessness
- Food insecurity

Good Governance

Safety and security
- Victimization
- Crime Severity Index
- Peace and security
- ★ Perceptions of neighbourhood safety after dark
- Childhood maltreatment
- Household emergency preparedness

Democracy and institutions
- ★ Confidence in institutions
- Voter turnout
- Representation in senior leadership positions
- Canada's place in the world
- Misinformation
- Trust in media
- Indigenous self-determination

Justice and human rights
- ★ Discrimination and unfair treatment
- Cyberbullying
- Confidence in access to fair and equal justice (civil)
- Confidence in access to fair and equal justice (criminal)
- Resolution of serious legal problems
- Incarceration rate

Health

Healthy people
- Health-adjusted life expectancy
- ★ Perceived mental health
- ★ Perceived health
- Physical activity
- Functional health status
- Children vulnerable in early development
- Fruit and vegetable consumption
- Healthy eating environments

Healthy care systems
- Timely access to primary care provider
- Unmet needs for health care
- Unmet needs for mental health care
- Access to long-term care
- Access to supplementary health insurance
- Unmet needs for home care
- Cost-related non-adherence to prescription medication

Society

Culture and identity
- Sense of pride in Canada
- Sense of belonging to Canada
- Shared values
- Indigenous languages
- Knowledge of official languages
- Participation in cultural or religious practices, recreation or sport

Social cohesion and connections
- ★ Sense of belonging to local community
- ★ Someone to count on
- ★ Trust in others
- Volunteering
- Satisfaction with personal relationships
- Loneliness
- Accessible environments

Time use
- Time use
- ★ Satisfaction with time use

Environment

Environment and people
- ★ Air quality
- ★ Drinking water
- Climate change adaptation
- Natural disasters and emergencies
- Satisfaction with local environment
- Active living environments
- Access to public transit

Ecological integrity and environmental stewardship
- ★ Greenhouse gas emissions
- ★ Conserved areas
- Canadian species index
- Water quality in Canadian rivers
- Natural capital
- Waste management
- Marine and coastal ecosystems

★ **Headline indicators: intended to provide a high-level assessment of overall quality of life in Canada.**

The Fairness and Inclusion lens is intended to inform policy and program development, leading to greater equity and equality, by assessing the distribution of outcomes for different populations in Canada.

The Sustainability and Resilience lens promotes long-term thinking by considering the trajectory of indicators in order to identify risks, build resilience and ensure that policy choices are contributing to a higher quality of life not only now but in the years ahead.

Is This a Good Time to Move Forward?

Governments can always find excuses to put ME/FM issues aside. But there are consequences for doing so. These consequence are felt by the the individuals affected and their families, by the health system, by the economy and by society.

Statistics suggest that there were close to a million Canadians with a diagnosis of ME, FM or both. That was before COVID which is known to trigger cases. We know that the ME/FM cohort had high rates of unmet health care needs, unmet home care needs, poverty and food insecurity, along with low rates of community belonging and employment. These are all indicators in the federal government's Quality of Life Framework.

We also know that exertion can be harmful to one's health, and yet the health system has failed to recognize ME and to advise people to manage their exertion. In fact, the health system often recommends exertion to ME patients. That means that the health system has been using a model of ME care that makes people sicker rather that healthier.

We also know that people with ME and FM keep going back to the medical system because they need help. This is frustrating and costly for patients and for health system as well.

We know that ME and FM are costing the economy. A US study concluded that "the estimated annual cost of ME/CFS, ranging from $225 billion to $305 billion, reflects both the direct strain on healthcare systems and the indirect costs of lost productivity and diminished quality of life". Converting for population, exchange rates and relative GDPs, that would be something like $25-33 billion dollars in Canada per year. The economic cost of FM has not been calculated, but it is likely around the same level (Quest 147, 2025).

As we said in our opening paragraph, we are very proud of our efforts and what we have achieved. But we are also dismayed by the lack of response from government.

Yes, this is a good time for government to address ME/FM issues. The sooner the better.

Additional Notes

Louise Arbour has been appointed the new Governor-General of Canada. She has an extremely strong background in human rights, including serving as the United Nations Commissioner for Human Rights.

While progress at the governmental level is frustratingly stalled, there is movement behind the scenes. Research is advancing and more guidance on diagnosis and treatment is available. People are approaching the health system more informed and some health professionals are more open than they were previously.

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