Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF LYNDA WATTS

I, Lynda Watts, say as follows:

1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe such information to be true.

2 I am giving evidence in my personal capacity.

Personal story

Our interactions with the mental health system

3 I am a carer of a son with dual disability, autism spectrum disorder (high functioning), and schizophrenia, formerly schizoaffective disorder and bipolar disorder. I have had firsthand contact with the mental health system for just over 16 years. There is hardly a service, program, initiative or "scheme"—the National Disability Insurance Scheme (**NDIS**)—that my son and I have not experienced across mental health. Within this, there has been some focus on alcohol and other drugs (**AOD**) and suicide prevention services as well.

4 All of this means that my son has experienced a vast range of services, together with the unrelenting challenges associated with each of the services:

(a) numerous hospital emergency department (**ED**) presentations;

(b) acute psychiatric unit stays of up to six months;

(c) area mental health services (**AMHS**s);

(d) Crisis and Assessment Treatment (**CAT**) teams;

(e) Mobile Support and Treatment teams;

(f) the Office of the Public Advocate;

(g) specialist clinics;

(h) mental health community support services;

(i) LGBTIQ programs;

(j) targeted programs such as Partners in Recovery (**PIR**);

(k) disability programs;

Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.

(l) mental health residential rehabilitation;

(m) supported residential services;

(n) housing and homelessness services;

(o) disability employment services; and

(p) psychosocial disability and complex support needs pathways within the NDIS.

5 There has been no let-up, and no end to my trying to figure it all out. And there has been no end to the near-tragedies, crises, risks, challenges and frustrations, nor the volume of private tears.

Consistent themes

6 I would like to note the most consistent observations that have emerged:

(a) that old adage, “one hand doesn’t know what the other hand is doing”;

(b) the anxiety around whether a service, program or funding stream will continue; and

(c) concerns about the skills and capabilities of workers, and whether competent workers would remain for the longer-term.

My background

7 From 2010 to 2017, I worked in communications, marketing, advocacy, events, volunteers, and membership with a community mental health organisation called Wellways.

8 In 2018, I did consultancy work with Eastern Melbourne Primary Health Network (**EMPHN**) and North Western Melbourne Primary Health Network (**NWMPHN**). Prior to that, I was a carer representative for Northern Melbourne PIR Consumer and Carer Reference Group, and also had the opportunity to develop a PIR forum series with Northern Melbourne Medicare Local (2015). During my time with the PIR Consumer and Carer Reference Group, I learned about the experiences of PIR participants in the northern region, especially their experiences of transition from PIR to the NDIS or other support services.

9 I was also involved with creating resources to aid that transition. I wrote a booklet for carers about supporting someone to transition from PIR to the NDIS. Together as a Reference Group, we all worked on an information brochure for consumers navigating from PIR to the NDIS. The Reference Group advised on not only the program itself and its implementation and improvement, but the transition to the NDIS.

10 I was also a carer representative for the NDIS Transition Support Project led by Flinders University to support Primary Health Networks (**PHNs**), service providers, and other stakeholders in the smooth transition of PIR, Personal Helpers and Mentors Service (**PHaMs**) and Day to Day Living (**D2DL**) program participants into the NDIS and, later, into psychosocial support services.

11 I learned a lot about the behind-the-scenes administration and bureaucracy involved in the transition. I was with people from all around the country who were part of the Organisational Reference Group for the NDIS Transition Support Project. I was exposed to workshops around the country and to the regular meetings of that Organisational Reference Group. That experience was probably most significant in terms of what I learned about the administrative processes in making that transition occur. It was quite extraordinary. It really made me very aware of what service providers and PHNs were dealing with at that time.

12 I have recently been asked to be the carer representative on the Clinical Governance Committee for EMPHN's *Regional Integrated Mental Health, Alcohol and Other Drugs and Suicide Prevention Plan*.

13 My work with EMPHN and NWMPHN came about through my involvement with the PIR Reference Group, and likewise the NDIS Transition Support Project. I was brought on to assist those PHNs in the co-design and development of their new psychosocial support services, funded under the Commonwealth's National Psychosocial Support Measure and Continuity of Support programs.

14 In the early stages, when we were doing all the co-design and development of those services with stakeholders, I was involved as the lived experience person. I was also on the tender evaluation panel at NWMPHN. So I have been on the ground with the development of those new psychosocial support services, which has been great in relation to the background I had with PIR and the NDIS Transition Support Project.

15 I was also involved in the transition phase of Commonwealth programs (PIR, PHaMs and D2DL), as these programs supported participants into either the NDIS or the new psychosocial support services (Continuity of Support and National Psychosocial Support Measure). Commonwealth transition funding allowed additional time for former PIR, PHaMs and D2DL participants to test their eligibility for the NDIS and, if not eligible, to transition to the new psychosocial support services.

16 At that time, I developed statewide communications for the sector and consumers and carers around the new psychosocial support services. Later, I assisted in the writing of an operational manual for the new psychosocial support services.

17 For me, all of this is quite a departure from a working life in the Australian film industry. It is by virtue of my lived experience as a carer for the past 16-plus years that my working experience in mental health has come about.

Interaction with Commonwealth and State services

Characteristics of PIR that made it a valuable and successful program

18 PIR worked through the complexities of so many services and so many different people contributing to my son's support. Previous to that, the services were not working in a coordinated fashion. So, PIR untangled the knots. I still recall seeing everyone around the table at my son's first care team meeting, getting to know each other and acknowledging each other's work; it was revelatory. The spirit of co-operation, once people understood what the program was about and what it was trying to do, was utterly inspiring. Our care team made it work with herculean effort from everyone.

19 Carers, if willing, were important members of the team, together with the consumer if they chose to participate in care team meetings. I was deeply involved from the start; I carried a lot of information and experience up to that point in time. I never felt that I was not included; I was included right from the start. I was really the conduit for so much held information and historical information that was very important.

20 People became accountable to each other, to each other's services and to the person being supported. Integration between the services became a reality, rather than just a buzzword. It was an absolute breakthrough program. At the PIR annual meeting, people came from around the country to speak. It just seemed that everywhere they were doing dynamic, innovative and integrated things.

Replicating the best characteristics of PIR in Victoria's future mental health system

21 My understanding is that PIR, for the program's duration, was very well funded to do the work it needed to do. I have been trying to think about how that could be replicated in Victoria's future mental health system. Any implementation would need to be funded adequately.

22 The coordination and integration function that PIR achieved may have a strong echo within the work the PHNs have done in developing their Regional Integrated Mental Health, Alcohol and Other Drugs, and Suicide Prevention Plans. These plans can be a key driver of integration and implementation between Commonwealth and State services. This seems to me like a very natural starting point and continuation point; there was so much that was good in PIR—how can that be situated within so much that is good and evolving from the regional plans?

The capacity for recent reforms to give people with lived experience a greater voice in regard to service delivery

23 In our experience, recent reforms have been highly variable in their success at giving a greater voice to people with lived experience. It really depends on the service provider and their willingness to take in the preferences of, and listen to, the people with lived experience.

24 It's still too early to tell how well the NDIS is succeeding in giving greater voice to people with lived experience of psychosocial disability. That shift in recognition of lived experience within the NDIS and NDIS service providers is going to take time at national, state or local levels.

25 A whole shift in recognition of the value of lived experience is now present in every major national, state and local mental health report. Reforms can be based on so much of what is already identified, particularly in service delivery.

Key characteristics that should be replicated in Victoria's mental health system

26 The characteristics that we should replicate include:

(a) drawing from the best of what is already happening in services;

(b) exemplary training of the lived experience workforce;

(c) a focus on evidence-based programs; and

(d) collaboration and communication.

27 We need to be drawing from the best of what is already happening in mental health services, because there are good things happening. We should be expanding those things that are working well and trimming back where there is less effectiveness.

28 We need to really look at where new and evidence-based programs are coming forth and showing good results. Sometimes I think we have so much of that information, so let's get it on the ground and working.

29 In my view, collaboration and communication are the keys in any reform measures.

Limitations of recent reforms and how they could be mitigated

30 In looking at the NDIS as a recent reform, we need to consider simpler systems and trusting that things will be okay with simpler systems. Our processes are very complicated, and it's almost like we have lost trust in something simpler.

31 The NDIS is still in process mode—working through the myriad of administrative functions before it gets to the truly person-centred stuff.

32 In terms of mitigation, we already have a lot of knowledge and existing reports, so let's move on what we have, without doing more and more consultation. Many of the reports even speak to that 'consultation fatigue'.

The complex support needs branch of the NDIS

33 I cannot speak highly enough of what my son and I have experienced with the complex support needs branch of the NDIS. It took a massive effort for my son to be taken up into the branch. I started approaches after the government announcement; some six months later he was in.

34 We got our own complex support needs planner, and she has worked in a highly competent fashion. I consistently sing the praises of the complex support needs branch to many; the communication, both written and by phone, has been consistent and timely.

35 There is a big gap emerging in the NDIS in care coordination. To the best of my knowledge, care coordination is not the role of the NDIS support coordinator. Care coordination is very important for the complex support needs branch. You would think care coordination would just automatically be a part of the complex support needs branch. Even specialist support coordination cannot carry all of the care coordination that is required, because you are dealing with support workers daily who may need new information, forms of guidance to address crises, critical appointments to be made, accommodation issues to be resolved, etc. It is a daily care coordination exercise, and I've found that to be a big gap.

The extent to which Commonwealth and State funded and run mental health services work together

36 There is a big disconnect that we have experienced between AMHSs, our local hospitals, specialist clinics, and other disability services. They are just not fully working together.

37 We had a recent example which was just extraordinary. My son was being transferred from one AMHS to another. While the administrative "paperwork" was underway, he presented to the local hospital's ED in acute psychosis. He was discharged at 3am—still in acute psychosis, unsupported, with no contact made by ED to me. Attempts to get him follow-up care at the appropriate AMHS resulted in a volley of "it's not our catchment, it's yours," resulting in *no* follow-up treatment for weeks on end, two more ED presentations (with 3am discharges), and no information sharing between ED, the

two AMHSs, and the NDIS accommodation service. I was left trying to expedite the AMHS transfer myself, together with support from the CAT team. Not one of the services (ED, AMHS, NDIS provider, CAT team) had an accurate account of any of the events, nor, it seemed, an ability to expedite crucial treatment required (in this case, of a complex needs NDIS participant).

Workforce

Great experiences of particular professionals and teams and characteristics

38 The best example of particular professionals or teams is the PIR support model and support facilitator in our case, who eventually became the NDIS support coordinator, and then has also provided specialist support coordination. Other good examples have been: certain case managers at AMHSs (and I have to stress, *certain* case managers); certain support workers at various service providers (both mental health and disability); and a complex support needs branch planner of the NDIS. Again, particular professionals have been very skilled.

39 At one of the AMHSs my son used to use, there is an absolutely superb consultant psychiatrist. She said something so encouraging in the early days that I even wrote it down as a quote. We had had so many people moving in and out of services: registrars, consultant psychiatrists, case managers, mental health support workers, etc. And she said, “Don’t worry, I’m not going anywhere.” It was beautiful. I almost wanted to cry.

40 These are the things that distinguished those excellent professionals:

(a) high level of personal integrity;

(b) great communication skills;

(c) wisdom and common sense; and

(d) honesty.

41 They were wise and full of common sense, which is valuable, especially when nobody knows quite what to do.

42 I valued their honesty, when they would sometimes say, “We just don’t know. We just don’t know the next steps.” Sometimes that is refreshing and what you want to hear, because everyone in the field at any one time is working in uncertainty and unpredictability, and it’s okay. It’s okay to say that to a family member or carer. If the person is saying it with a high level of personal integrity and sincerity, then I do not mind hearing that. Oddly enough, it can sometimes be a comfort to hear, “Nobody really knows, and we kind of have to move day by day.”

43 For me personally, if I can contact a professional and they respond, that means so much. It is the lack of communication—**the outright deafening silence**—and the absence of follow-up that are among the most disheartening and sometimes devastating situations that are characteristic of the system.

Most important factors in supporting lived experiences workforces

Training and supervision

44 Superb training and supervision will be important factors. Even in my role with the National NDIS Transition Support Project, I felt like, “Gosh, do you know what it is that you want me to do? How would you like me to contribute?” I was learning as I went, trying to grasp the nature of my contribution. Training and supervision are so important, and I think people are more than willing in the lived experience workforce to take that up. I know for myself I would be very grateful if it was offered.

Flexible schedules and job stability

45 Likewise, other important factors are flexible schedules for people and job stability. When there was a whole re-commissioning several years ago of mental health services in Victoria, job stability for the peer workforce was very uncertain. Now that we are in the NDIS environment, there is further uncertainty with our peer workforces. So job stability is an important factor in supporting peer workforces to thrive.

Professional acknowledgment of peer workforce

46 There is work going on for a peak professional body, and the new Peer Workforce Development Guidelines are being created by the National Mental Health Commission. The peak professional body and the workforce guidelines will be important factors in a thriving peer workforce. My personal experience, of working alongside people with lived experience in reference groups and committees, is that when they are offered peer support positions or a mental health consultancy, it has just made all the difference to them. It has been life-changing for them, and they have just stepped up into that space in such a dedicated way. It has been lovely to see.

47 Of course, organisations need to be very open to new ways of developing and managing the new peer workforce. The cultural mindset needs to be that peer workers are central to the services, not just an adjunct to existing teams.

Future aspirations

Importance of communication between services for improving consumer experience

48 I have already indicated the importance of good care coordination, which contributes to better communication between services. That has been for the most part absent, except for PIR and a short period of time when state services got funding specifically for care coordination, and we had a skilled care coordinator. This was a number of years ago.

49 Care coordination means someone has all-around oversight of what is going on, who needs to know what, when, what's appropriate to convey, the concerns and privacy issues. PIR took up that care coordination so effectively.

50 Skilful care coordination addresses issues of communication (or lack thereof) between services and promotes service integration. Effective care coordination can alleviate the immense frustrations, experienced by carers, of unresponsive services: phone calls never returned or returned weeks later after a crisis, emails never responded to, timeframe commitments never honoured, etc. I've always felt that good communication can do 50 to 75% of the job in improving services. Good communication is not only about providing information, but about engendering confidence in consumers and carers. It is about addressing their stress, helping them feel connected and not isolated, and increasing that consumer or carer's ability to "hang in there". Care coordination also addresses the problem of "one hand doesn't know what the other hand is doing", by ensuring that communication is happening between services and there are appropriate follow-ups. It breaks down the proverbial silos, it helps staff to connect with other services, and form solid working relationships and friendships.

Opportunities for greater coordination between services

51 When the PHNs have their integrated regional plans, we need to fund the implementation of them. The good integration actions are there, so we need to put people on the ground whose job it is to make these services work together.

52 I understand, too, that appropriate information-sharing is a big part of this. It is a fundamental element in communication. Being able to share appropriate information, particularly when someone is presenting with highly complex needs, can make all the difference in support and treatment. For instance, if any of the appropriate information had sat with the ED my son had gone to three times, or had sat with the AMHS, he would not have been out on the streets at 3am in the morning in acute psychosis. It just would not have happened. There would have been records to show that we've got a very complex individual here who is an NDIS participant, who is a client of such and such AMHS, who has recently been seen for this purpose—maybe in the last week—

and here he is. That would signal the need to be very careful, to exercise the duty of care, because that information is known. So a 3am self-discharge of someone in acute psychosis three times would not happen. And we know that this is happening. We know that this is happening.

53 Also relevant to greater coordination is something that has been around for a while, an "advance statement". The number of times I've had to say to services, "But didn't you see the advance statement? Don't you have that? Why, then, has that medication been put into the mix? The instruction is in the advance statement." Again, this is a fundamental information-sharing area.

Other thoughts

54 I cannot emphasise this enough, that there are wonderful, skilled, kind workers everywhere, but they are as much caught up in the system and the dysfunction as are consumers and carers. These skilled workers stand out because they are not necessarily the norm. Skill levels vary from service to service, person to person, but it is my observation that gifted practitioners are out there. We need to retain them.

55 My biggest concern and my biggest desire in this process is that it will be productive and beneficial. It's not about tearing down services or the workforce. It's about building up and acknowledging where good work has been done, so more good work can be done.

sign here ► Lynda-Lee A. Watts

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