Nowhere to Turn:

Institutionalization by Default, Not Design

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CAMH's Dual Diagnosis and the Forensic Mental Health System conference

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Introduction

1. Good morning! Thank you for that introduction and thank you for the opportunity to speak at your conference today. It's an honour for me to be here to meet with professionals in the developmental services sector and the forensic mental health system.

2. What brings us together today are issues of great importance to our society. Issues that need to be addressed.

3. You know, in my job, I have become increasingly familiar with the prevalence of mental health issues in our society. I have also gained a lot of insight into the challenges faced by individuals with developmental disabilities, including those living with dual diagnosis.

4. Today, all levels of government and many institutions struggle to respond to the increasing demands on the education, health, social services, justice and correctional systems posed by the unique and complex needs of those living with developmental and mental health disabilities.

5. To that end, I want to congratulate CAMH on its new program, the Forensic Specialisation Dual Diagnosis Service, which will help individuals with dual diagnosis within the forensic mental health system transition into the community. I look forward to hearing more about this partnership between the Ministry of Health and Long-term Care and the Ministry of Community and Social Services.

6. As many of you know, I released a report last August about services for adults with developmental disabilities in crisis. Before discussing the report, I'd like to provide an overview of my office and the role of the Ontario Ombudsman, and explain how our Office adds value for the people of Ontario by promoting accountability, transparency, and fairness in public sector governance.

Ontario Ombudsman: Overview

7. You know, we get asked this all the time: What exactly is it that the Ontario Ombudsman does? How do you approach relationships with stakeholders, citizens, and public sector bodies? And how can *your office help me?*

8. Our Office was established in 1975. I'm an impartial, independent Officer of the Legislative Assembly. I was appointed by an all-party Committee of the Legislature and not by the Government. My Office investigates public complaints about provincial government bodies and municipalities, school boards, and universities. An Ombudsman promotes accountability, transparency and fairness by receiving complaints from citizens about their government or a public sector body.

9. We help resolve issues related to individual complaints, and we address systemic issues by proposing corrective actions.

10. One of the first things I did when my term as Ombudsman began on April 1 of last year was develop values, mission and vision statements for the Ombudsman's office.

11. Our Mission is that we strive to be an agent of positive change by promoting fairness, accountability and transparency in the public sector. And our Vision is a public sector that serves citizens in a way that is fair, accountable and transparent.

12. The legislative framework within which we operate, and the productive and appropriate relationships we have built over time, enable us to effectively resolve issues – and we strive to do that expeditiously and at the lowest level possible.

13. My Office handles more than 22,000 complaints from the public each year. Generally, we look at administration and process, to determine if a public body followed the correct procedures.

14. But it is important to know that the Ombudsman is not an advocate for complainants. We don't take the side of the complainant or the public sector body. To be credible, to gain the trust of stakeholders, and fulfill our role as it was contemplated over 200 years ago when the first modern parliamentary Ombudsman was established in Sweden, we must be independent, impartial, and deal with complaints confidentially.

15. However, we don't just look at complaints in isolation.

16. We look for trends or patterns in complaints so we can identify and address the root causes of repetitive complaints – what we call the systemic issues – in order to provide recommendations for corrective action in order to prevent those issues from recurring.

17. Systemic investigations involve reviewing documents, conducting interviews, and issuing recommendations to the organization in question – our investigation into services for adults with developmental disabilities was one of these.

18. We do not have the power to compel public sector bodies to accept our recommendations.

19. And yet, nearly all of our recommendations from the 38 systemic investigations we have conducted over the years have been accepted.

20. That's because we use moral suasion and our power is in our voice.

21. By compiling irrefutable evidence, by telling compelling stories, by conducting a thorough, fair and balanced analysis, and by making feasible recommendations, we make it hard for a public sector body not to accept our recommendations.

22. So, our systemic investigations are impactful and far-reaching.

23. But every day, we help vulnerable individuals with problems – like complaints about the Ontario Disability Support Program, the Public Guardian and Trustee, Ontario Works, healthcare and drug funding, or developmental services programs.

24. We encourage you to consider our Office when dealing with a particularly thorny or bureaucratic problem related to one of Ontario's public sector bodies. We might be able to help.

Nowhere to Turn Report

25. So we're here today to discuss solutions for helping adults with developmental disabilities, many of whom have been left in the cold by a system that relies on institutionalization by default. In our 2016 report, *Nowhere to Turn*, we found shocking instances of adults pushed aside by the very system that was created to build them up.

26. During our investigation, we focused on how the Ministry of Community and Social Services responds to situations of crisis, and its process for co-ordinating, monitoring, and facilitating urgent access to resources for adults with developmental disabilities.

27. Our investigation was comprehensive, spanning more than four years, tens of thousands of pages of documentation, more than a thousand complaints, and hundreds of interviews. What we found will not be a surprise to anyone in this room.

28. We found that despite the government's intent to transform the system away from the former institutional model, in reality some adults with developmental disabilities continue to find themselves excluded from their communities, particularly those who live with complex conditions or serious behavioural challenges.

29. Institutional care no longer happens through design, but by default. There are far too few community placements that can accommodate the needs of individuals labelled as 'hard to serve.' With nowhere else to turn, those in crisis can find themselves inappropriately housed in a variety of institutional settings, from hospitals to jails.

30. My team conducted 221 interviews and reviewed more than 25,000 documents over the course of the investigation, in addition to working individually with hundreds families to help them access the services, supports, and funding they needed.

31. The report includes 18 of the extreme and egregious cases my Office handled. The cases touch on a variety of issues we observed over the course of the investigation, including abuse, abandonment, incarceration, and the hospitalization of individuals with developmental disabilities.

32. What we observed in our investigation was a fragmented, confusing, and complex assortment of hundreds of community agencies and local processes, which were nearly impossible for many individuals and their families to navigate.

Institutionalization by Default

33. During our investigation, we found that a modern-day version of institutionalization continues to exist in the province of Ontario, due to the lack of supports, services, and rigorous monitoring in the sector.

34. Although in principle the government has criticized the concept of placing adults with developmental disabilities in large institutions, the reality, as you well know, is that hundreds of adults with developmental disabilities still find themselves living in institutional settings in Ontario.

35. The lack of appropriate residential resources in the community has, by default, resulted in many adults with developmental disabilities being inappropriately housed in hospitals, long-term care homes and even in jails, for prolonged periods.

Peter's story

36. There are times when an adult with a developmental disability will require acute care within a hospital setting for medical issues. Individuals with a dual diagnosis may need to be admitted to hospital to address acute psychiatric issues, often in specialized settings.

37. All too frequently though, after their acute symptoms have subsided with treatment, adults with developmental disabilities remain hospitalized, often in psychiatric units, because there is no alternative safe and secure housing for them in the community.

38. This situation is unacceptable. Developmental disability is not an illness, nor should it be treated as one. Individuals who remain hospitalized unnecessarily can be exposed to infection, and these facilities do not have the training and resources to provide appropriate programming and supports.

39. And of course, this can result in fewer hospital beds being available to those who need them for medical reasons.

40. During our investigation, we received 79 complaints that raised the issue of hospitalization as a Band-Aid solution for the lack of residential placements in the developmental services sector. Some of the individuals we encountered had been hospitalized for years. We worked with the Ministry of Community and Social Services to address these cases and successfully facilitated moving 20 people from hospitals to more suitable community placement.

41. Let me tell you about one of the people we helped. Peter – that's not his real name, but it's what we called him in the report – Peter had been diagnosed on the autism spectrum, and had been placed in residential care at the age of 15.

42. Since 2002, he had spent the better part of 12 years in psychiatric hospitals, after the agency that was providing him with adult group housing found they could not handle his aggressive behaviour. Peter functions cognitively at the level of an 18-month-old child. He is non-verbal, often crying and crawling like baby.

43. Our office first learned of Peter's case in November 2013 from a social worker at the mental health centre where he was living on the schizophrenia unit, even though he had not been diagnosed with schizophrenia. The social worker was concerned that Peter was progressively deteriorating as the result of his extended institutionalization, and was trying to help his mother find him services.

44. We were told that Peter's days on the unit typically began with him sitting on the floor. If he was not kept active, he became increasingly aggressive. He often hit other patients, and was placed in physical restraints a couple of times a week.

45. Understandably, the psychiatric hospital was not equipped to provide Peter with the developmental services, staff and structured activities necessary to stimulate and calm him. In 2012, arrangements were made for support workers to take him out for weekly outings. However, these were insufficient to meet his needs.

46. Peter had been given the highest priority on the waiting list for a residential group placement in 2006, but he had never been selected for any of the residential vacancies arising in the community.

47. A senior hospital official who was involved with attempting to facilitate Peter's transition to the community explained to us that Peter was not considered a priority because he had a place to live - the hospital.

48. Peter's case was just one of those that our Office has worked on actively and followed closely. We made repeated inquiries and alerted senior Ministry officials to our concerns about his continued hospitalization. Finally, after 12 years in institutional purgatory, Peter was approved for funding to allow him to move to a placement created for him. He is now in his new home in the community, where we understand that he is doing well.

Christine's story

49. In addition to the ongoing institutionalization of adults with developmental disabilities in the hospital system, we observed institutionalization in another form – through incarceration.

50. It is shocking that we continue to jail individuals with developmental disabilities, some assessed as functioning at the cognitive levels of young children, and often living with dual diagnosis. During our investigation, we heard about several cases where incarceration became the failsafe when the developmental services sector could not provide adequate supports.

51. We received 27 complaints about adults with developmental disabilities who were charged criminally and another 19 complaints involving the issue of incarceration of due to insufficient supports and services.

52. Let me tell you about Christine. Her story was also in our report. Christine was diagnosed with a developmental disability, attachment disorder, anxiety, and depression. She has been connected with developmental services since she was three. However, she has had challenges with the system; she is high-functioning and strives for independence, but she is also impulsive, prone to risky behaviour, and capable of violent outbursts.

53. Her heightened fight-or-flight instinct also causes her to flee when she feels anxious.

54. Since she turned 18, Christine has spent little time in the family home, where she has been assaultive, particularly towards her mother.

55. Multiple attempts were made to find her a suitable community placement. However, she was unsuccessfully matched with 20 different family home support providers, and even more structured residential living arrangements have failed to meet her needs.

56. Christine's assaultive conduct has posed a safety risk for developmental support staff and she has faced multiple criminal charges while in community living homes.

57. Christine was initially considered a candidate for the court diversion program, but her history of breaching court-imposed conditions has led to dozens of arrests and numerous convictions and incarcerations.

58. Christine is a safety risk for staff in the developmental services system. She does not fit the existing system or any of the group homes operated by the local community living agency.

59. By default, it has been local health, police, justice and correctional officials who have had to manage her dysfunctional behaviours.

60. Eventually, Christine was moved to a permanent residential placement. But in fall 2014, she was arrested for assault and breach of probation. In February 2016, a service agency told us that Christine is living in the community. She has an apartment and access to staff supports, and has been doing better. She has been out of jail since October 15, 2015.

61. The vicious cycle of incarceration that Christine experienced is a symptom of the inconsistent and uncoordinated approach pursued by the developmental, health, justice and correctional services sectors towards adults with developmental disabilities in crisis.

62. The resources expended by various provincial and local agencies to attempt to address Christine's volatile conduct have been significant, but often ineffective.

63. These are just two of many cases illustrating how institutionalization by default - in hospitals and jails - continues to be the stop-gap measure when there are no alternative safe and secure housing options available in the community for these individuals.

64. People like Peter and Christine, who present unique challenges to service providers, should not be left adrift. Housing them in hospitals or jails isn't the answer; these systems simply aren't equipped to deal with these individuals.

Our report and next steps

65. The report was released on August 24, 2016. During our investigation of these complex and far-ranging issues, the government – to its credit – did make improvements to how it responds to these crisis situations. It also committed an additional $810 million over three years to strengthen services and supports. But more needs to be done.

66. For example, in our report, we recommended:

Creating an online provincial inventory of crisis beds easily accessible to developmental services and police officials.

Ensuring that crisis workers are available to adults with developmental disabilities who require urgent assistance to access temporary residential placements.

67. Obtaining regular information from hospitals across the province concerning emergency visits and admissions of adults with developmental disabilities, including details about hospital stays, their length, and their outcomes, in order to plan for appropriate developmental supports and services.

68. Ensuring that there are specialized case management and court support services available for all individuals with developmental disabilities involved with the criminal justice and correctional system.

69. As soon as our report was released, the Minister of Community and Social Services accepted all 60 recommendations and committed to implement them.

70. However, since our report was released more than six months ago, we have continued to receive complex and disturbing complaints from parents and families of adults with developmental disabilities, which my staff work to resolve on a case-by-case basis.

71. Since the report was released, we have received dozens of new cases, and that number grows weekly. It is clear evidence that not enough is being done to help vulnerable people in these sectors.

72. Earlier this month, we received the Ministry's six-month update on its progress implementing my recommendations. While the Ministry is off to a good start, it acknowledged that there remains much work to do to transform developmental services in Ontario.

73. There are three phases to our work:

1 – Investigation
2 – Reporting
3 – Follow-up on implementation

74. We are at the third phase with this investigation. Our work doesn't end just because the report is published.

75. In the coming weeks and months, we certainly hope to see more concrete and tangible evidence that the Ministry is making sufficient progress on implementing our recommendations, and we will be meeting with officials regularly to ensure this happens.

76. We are anxious to see the finalized plan for implementation and tangible progress on the recommendations.

77. I do hope we will be able to continue to work collaboratively and productively with the Ministry in order to achieve our shared goal of a developmental services sector that meets the needs of some of the most vulnerable citizens in our province.

Conclusion

78. We recognize that this is a challenging sector and that transformational change cannot happen overnight.

79. But institutionalization by default continues to occur when service gaps and inadequate supports leave adults with developmental disabilities and their families with nowhere to turn. This has to change, and change *soon.*

80. Nonetheless, the transition towards a community-based approach to the developmental services sector - promoting social inclusion, individual choice and independence - is a positive policy shift away from the old model of institutional care.

81. Collaboration across sectors and ministries is needed to ensure that individuals are receiving appropriate care in the appropriate residential and community settings.

82. CAMH's new program, the Forensic Specialisation Dual Diagnosis Service, is one such partnership that will make a tremendous contribution to that progress.

83. I thank you for your time and attention today, and for the important work that you do. Have a great conference. If you would like a copy of our report, there are some copies in the back. And it's available on our website.