



Health Care Access Research
and Developmental Disabilities

HEALTH CARE ACCESS RESEARCH AND
DEVELOPMENTAL DISABILITIES (H-CARDD)

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Adults with developmental disabilities plus a mental illness or addiction (DD-plus)

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About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and wellbeing of individuals with developmental disabilities through improved health care policy and services. H-CARDD research is conducted by dedicated teams of scientists, policymakers, and health care providers, working collaboratively.

H-CARDD's partners include the Ontario Ministry of Community and Social Services, Ontario Ministry of Health and Long-Term Care, Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences, Surrey Place Centre, University of Toronto, University of Ottawa, Queen's University, York University, Lakehead University, Sunnybrook Hospital, University of Ontario Institute of Technology, and Women's College Hospital.

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Main Messages

Main Messages

- Adults with developmental disabilities and a mental illness or addiction (**DD-plus**) represent a relatively small proportion of the population but they tend to be poorer, sicker and use more intensive health services than the general population.
- Even after controlling for factors that often explain high service usage, such as income and continuity of care, this population still has higher rates of problematic service use (specifically, 30-day readmissions, 30-day repeat ED visits, and ALC days) than other individuals.
- The subgroup of adults with developmental disabilities and both a mental illness and addiction ('triple diagnosis') is particularly complex and has the highest rates of service use.
- Improving outcomes for individuals with **DD-plus** requires a better understanding of what factors, besides simple access to primary care or better continuity of care, are creating their high rates of problematic service use.
- Key areas to consider for the **DD-plus** population are –
 - Specifically tailored discharge planning and post-discharge follow-up to improve smooth transitions from hospital to community
 - Coordinated combinations of mental health, addictions, physical health, and social services that are easy for them to navigate
 - Addressing the impact of negative provider perceptions of developmental disabilities and of addictions on the quality of care they receive
 - Improving the capacity and comfort level of providers for dealing with them.

Background

We know from our previous research that adults with developmental disabilities (**DD**) are an extremely vulnerable population with complex health needs. In comparison with the general population, they live in lower income neighbourhoods and have higher rates of chronic illness. They also use and re-use more health care services, including physician services, emergency and inpatient hospital services. (Lin & Balogh, 2015; Lunsky, Klein-Geltink, & Yates, 2013). In particular, we found that almost half of adults with DD have a mental illness, a much higher rate than the general population.

Historically in Ontario, individuals with the combination of **DD** and mental illness have been a priority population. However, there has been relatively little research looking at this combination systematically across the province. In addition, there have been anecdotal reports that, for some individuals, having an addiction also complicates their care. The limited research has focussed strictly on mental illness and ignored addictions, possibly because of the misconception that those with DD do not use drugs or alcohol. Consequently, there was a question of how mental illness and addictions occur in the DD population and whether or not they are associated with things like chronic disease or how services are used and reused.

The purpose of this project is to look more closely at adults with **DD** who also have mental illness or addictions (MI/A). Our objectives are to use the H-CARDD cohort (see description below) to:

- Describe the prevalence of the combination of DD plus a mental illness or addiction (**DD-plus**) among adults in Ontario
- Evaluate whether the higher rates of chronic disease, service use, and repeat service use previously reported for the entire H-CARDD cohort also apply to the subpopulation with **DD-plus**
- Evaluate the impact of other factors on this population – including sociodemographic factors like age, clinical factors like chronic disease, or system factors like physician supply.

Methods

Data source

This project was conducted using the H-CARDD cohort. The H-CARDD cohort is comprised of 66,484 adults in Ontario, between the ages of 18 and 64, who were identified through administrative data sources as having a **DD**. The H-CARDD definition of **DD** reflects that of Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, which defines **DD** as "prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations a) originated before the person reached 18 years of age; b) are likely to be life-long in nature; and c) affect areas of major life activity such as personal care, language skills or learning abilities, the capacity to live independently as an adult or any other prescribed activity". Intellectual disabilities, autism spectrum disorders, Down syndrome and fetal alcohol spectrum disorders all fit this definition (Ministry of Health and Long-Term Care & Ministry of Community and Social Services, 2008).

The H-CARDD cohort was created using two data sources, administrative health data and the Ontario Disability Support Program database, to allow better identification of adults with DD in Ontario. At the provincial level, using only one data source would have resulted in between 34% and 37% of the cohort being excluded (Lin et al., 2014). The use of multiple data sources makes the H-CARDD cohort the most comprehensive portrait of adults with DD in Ontario. However, due to the nature of administrative data, we know there may be individuals with DD who are not captured in the cohort. The information in this report reflects data from the 2009/2010 fiscal year.

Defining the groups of interest

In order to look more closely at the subgroup of adults with DD and a mental illness or addiction, we performed two kinds of comparisons: one at a broad level and the second at a more detailed level (for the full list of codes included in our definition of mental health and addictions see Appendix A).

First, at a broad level, we compared the following groups:

- **DD-plus** = persons with DD with mental illness and/or addiction
- **DD-only** = persons with DD without mental illness or addiction
- **Adults-without-DD** = a random sample of all Ontarians (18-64 years old) without **DD**

Then, to get a more detailed understanding of these groups, we divided the DD-plus group into 3 subgroups. We also compared them to those individuals in the Adults without DD group who also had a mental illness and/or addiction to make a more 'level playing field'.

- **DD-plus (only MI)** = DD plus a mental illness only
- **DD-plus (only A)** = DD plus addiction only
- **DD-plus (both MI/A)** = DD plus both a mental illness and an addiction
- **MI/A-only** = the subgroup of **Adults without DD** with a mental illness and/or addiction

Analysis

In this report we provide descriptive information for these three groups and **DD** subgroups on their neighbourhood income and chronic diseases. We also describe their health care use (doctors, hospitals, and emergency departments) and what we are calling their ***Problematic Service Use Outcomes***. These are returning to hospital within 30 days after they were discharged, returning to the emergency department (ED) within 30 days after they had a previous ED visit, and remaining in hospital even though their physician has determined that they are ready to be discharged. In the graphs and tables which show our results, these are labeled: **30-day readmissions, 30-day repeat ED visits, and ALC days** (where ALC stands for Alternate Level of Care).

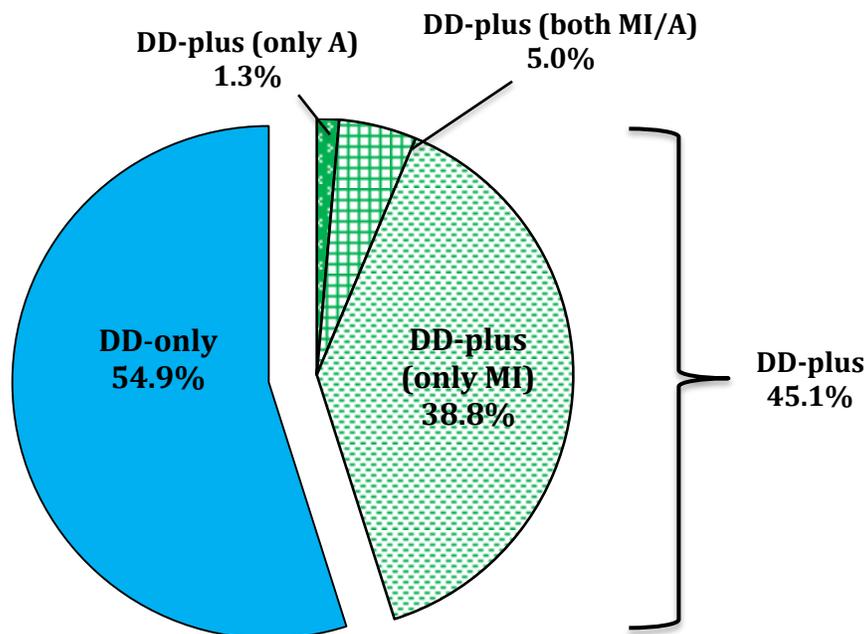
There are at least two reasons why these outcomes are considered ‘problematic.’ First, we assume that most people would prefer not to return to hospital or the ED or to stay in a hospital bed longer than they need to. Second, it is believed that these service outcomes could occur less often or be even prevented if we improved the health care system.

Besides describing these ***Problematic Service Use Outcomes***, we went one step further in our analyses. Because these outcomes can be influenced by many other factors besides a person’s disability, we used a statistical approach called multivariable regression analysis. This approach allows us to control for other factors (for example, age and sex) that may differ among the groups being compared and may affect the outcome. We can then see if there is still an association between having a **DD** and experiencing one of these service outcomes.

The results from this further analysis are described in the pages that follow as comparisons with ‘MI/A-only’ and as results reported for ‘Among the DD-plus’. They are also provided in more detail in Appendix B along with a list of the factors that we controlled for.

Results

Prevalence

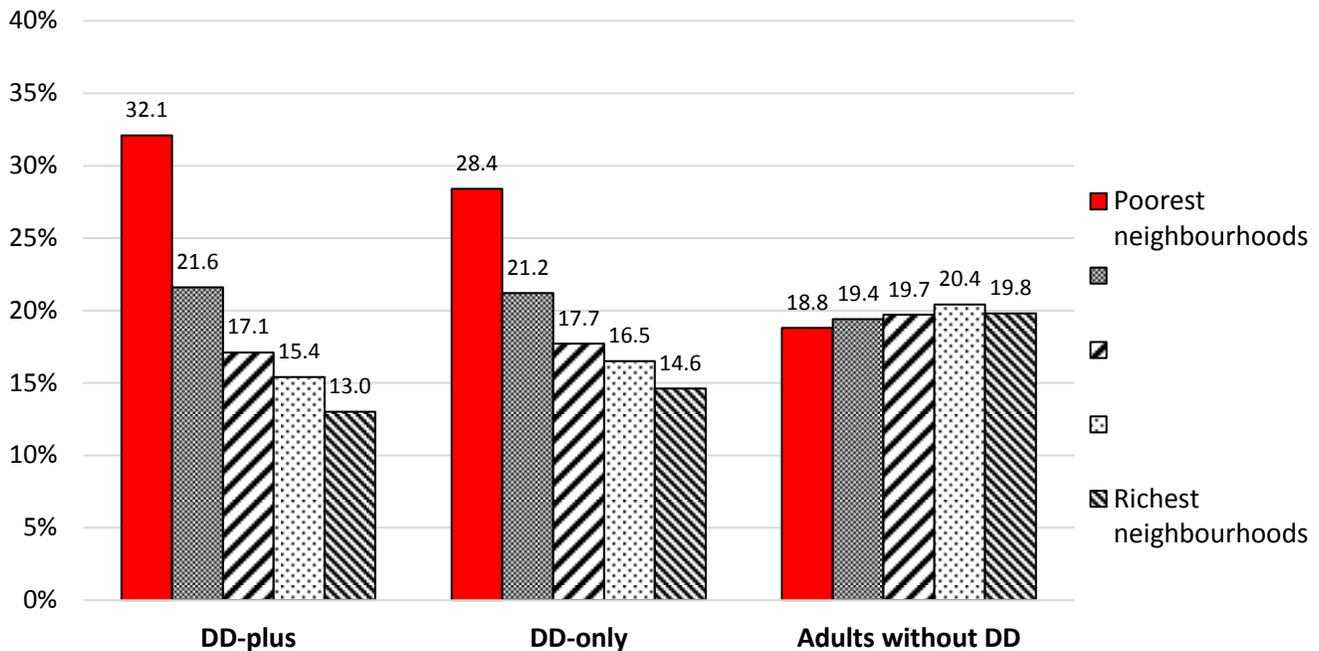


- The H-CARDD research program identified 66,484 adults with developmental disabilities (**DD**), aged 18-64, in Ontario in 2009.
- Almost half of this group (45.1% or approximately 30,000 individuals) had both **DD** and a mental illness or addiction (**DD-plus**).
- In comparison, **adults without DD** have much lower prevalence of mental illness and addictions (26.4% - Lunskey et al., 2013).
- Among the **DD-plus** subgroups, the vast majority have a mental illness (97% or approximately 29,000 individuals).
 - Most have only mental illness (~ 26,000), that is, **DD-plus (only MI)**.
 - A smaller group have both mental illness and addictions, that is, **DD-plus (both MI/A)**.
 - Only a small percentage (~900 adults or just over 1% of adults with **DD**) have only an addiction, that is, **DD-plus (only A)**.
 - The adults with addictions (**both MI/A** and **only A**) make up 6.4% of all adults with **DD**. This is much higher than the percent for **adults without DD** (3.5%) and also much higher than the rates published in the scientific literature (0.5 to 2.6%: Lin, Balogh, McGarry, Selick, Dobranowski, Wilton, & Lunskey, submitted).

Key finding

Adults with **DD** have higher rates of mental illness and addictions than previously thought.

Neighbourhood Income

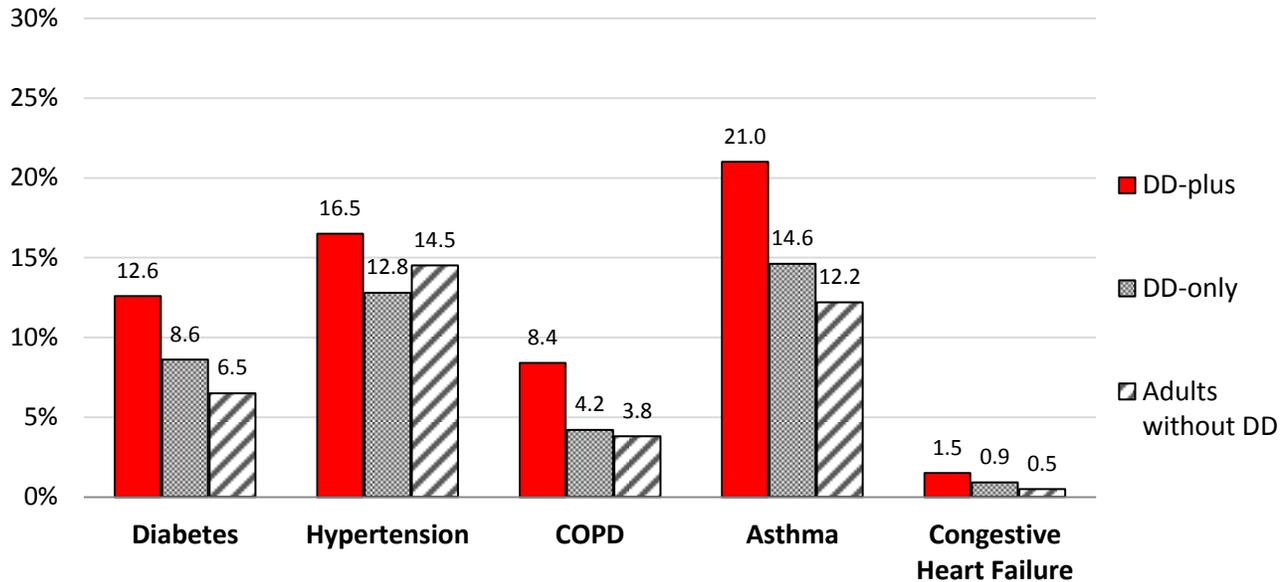


- Previous work (Lunsky et al., 2013) reported that **DD** is strongly associated with living in areas with lower neighbourhood income.
- A closer look at the figure above shows that within the H-CARDD cohort, adults with **DD-plus** are 1.7 times and those with **DD-only** are 1.5 times as likely to live in the poorest Ontario neighbourhoods compared to **adults without DD**.
- Similarly, the two groups of adults with **DD** are the least likely to live in the richest neighbourhoods.
- Among the **DD-plus** subgroups (not shown), adults with **addictions** (that is, those with **both MI/A or only A**) are the most likely (40%) to live in the poorest neighbourhoods and the least likely (less than 10%) to live in the richest neighbourhoods.

Key finding

Adults with **DD** are more likely to live in poorer neighbourhoods than **adults without DD**, and among **DD**, those who also have an **addiction** are even more likely to live in a poor neighbourhood.

Chronic Disease

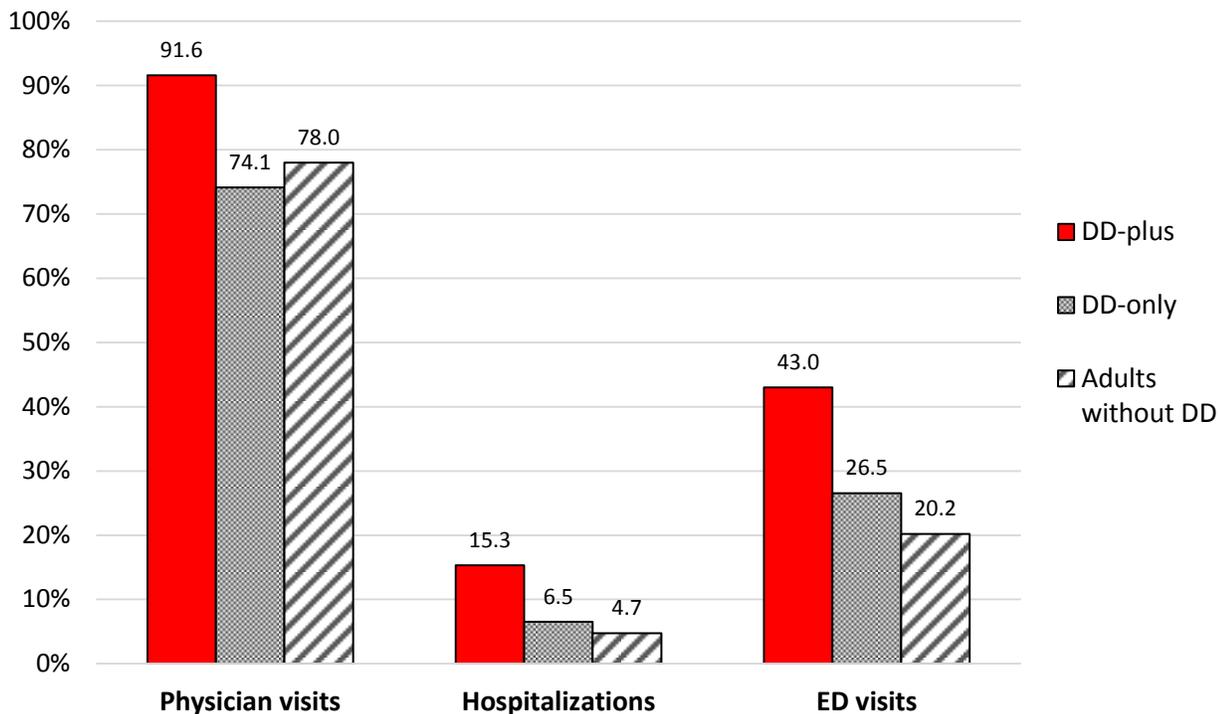


- Previous work (Lunsky et al., 2013) reported that **DD** is associated with higher rates of chronic disease than the general population.
- Our current results show that these higher rates are driven by the **DD-plus** subgroup.
 - In the graph above, adults with **DD-plus** have the highest percentages of diabetes, hypertension, chronic obstructive pulmonary disease (COPD), asthma, and congestive heart failure.
 - The rates for the other two groups (**DD-only** and **adults without DD**) are closer to each other than to the **DD-plus** group.
- Among the **DD-plus** subgroups (not shown), the rates of chronic disease are fairly similar for all subgroups **except** for COPD and asthma.
 - For COPD, adults with **addictions** (that is, those with **both MI/A** or **only A**) had rates that were nearly double the rate of adults with **DD-plus (only MI)** (14% vs 8%).
 - For asthma, adults with **both MI/A** had a rate almost 1.5 times the rate of adults with **only MI** (29% vs 20%).

Key finding

Adults with **DD-plus** have higher rates of chronic disease in comparison with adults with **DD-only** and **adults without DD**.

Service Use (past year)



- Adults with **DD-plus** have the highest rates of using physician, hospital, or emergency department (ED) health care compared to adults with **DD-only** or **adults without DD**.
- The majority of those with **DD-plus** (over 90%) have visited a physician at least once in the last year.
- They are also more than twice as likely as **adults without DD** to be hospitalized (15.3% vs 4.7%) or to have an ED visit (43.0% vs 20.2%).
- Among the **DD-plus** subgroups (not shown), adults with **both MI/A** are much more likely to be hospitalized or have an ED visit.
 - Adults with **both MI/A** have the highest rate of hospitalization (31%). This is more than twice the rates for adults with **only MI** (13%) or **only A** (12%).
 - They also has the highest rate of visiting the emergency department – 65% compared to 40% (**only MI**) and 47% (**only A**).

PHYSICIAN VISITS →

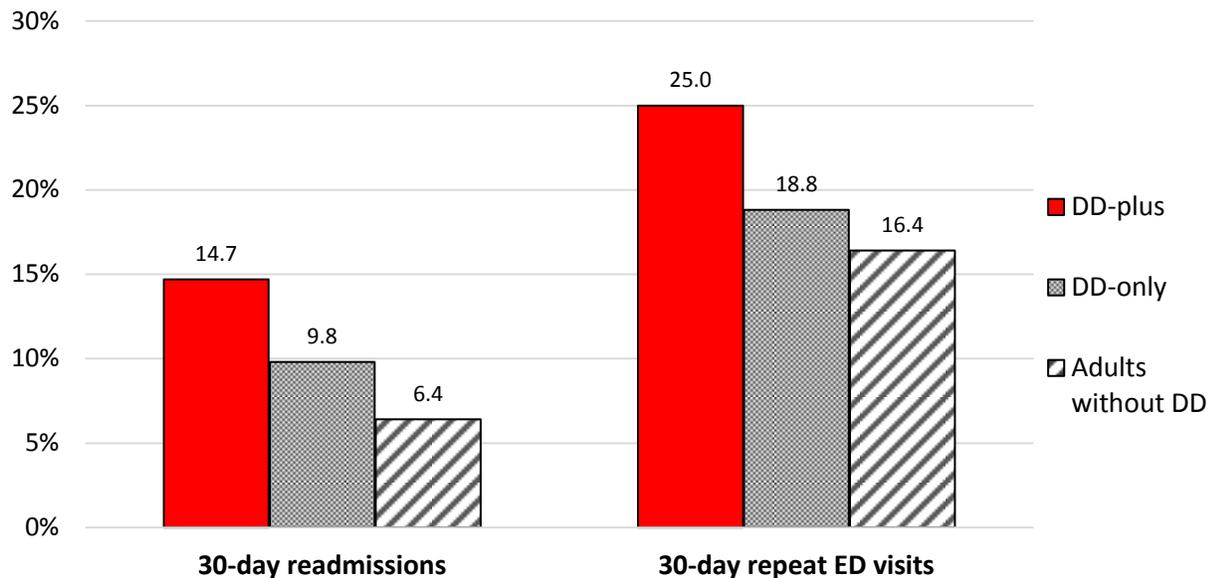
The OHIP claims data includes physician visits that were billed or 'shadow billed' to OHIP.

While physicians paid by other billing models may be missed, the majority of their activities continue to be captured in the OHIP database (Chan & Schultz, 2005; Henry, et al., 2012).

Key finding

Adults with **DD-plus**, and in particular adults with **both MI/A** ('triple diagnosis'), have the highest rates of using hospital and ED health care.

Repeat Service Use



- Adults with **DD-plus** are the most likely to have a 30-day readmission or a 30-day repeat ED visit.
- This is surprising since they also have high rates of seeing physicians (previous graph), which is thought to protect against repeat hospitalization or ED visits. One possible explanation is that, although they are seeing physicians, they are not receiving the right kind of care. Another possibility is that because they are a very complex group, the physician care they are receiving is still not enough to meet their needs and keep them out of hospital.
- We also tried comparing the **DD** groups with another group of adults with mental health or addictions problems but no **DD** (which we have labeled **MI/A-only**). The adults with **DD-plus** and **DD-only** still had higher repeat service use (not shown).
- To see whether this pattern held true even when other factors were controlled, we controlled for factors such as age, sex, income, and continuity of care and still found that this difference remained (See Appendix B).
 - **DD** groups are 1.66 times (**DD-plus**) and 1.27 times (**DD-only**) more likely than the **MI/A-only** group to be readmitted within 30 days.
 - And, they are 1.37 times (**DD-plus**) and 1.14 times (**DD-only**) more likely to return to the ED within 30 days.

30-DAY READMISSION→

When an individual is admitted to hospital and then has another hospital admission within 30 days of discharge.

30-DAY REPEAT ED VIST→

When an individual visits the ED and then comes back to the ED within 30 days of discharge.

Why do we look at this?

Although sometimes there is no way to avoid multiple hospitalizations or ED visits, often it is a signal that the individual did not receive the right care in hospital or the right follow-up care in the community.

- Among the **DD-plus** subgroups (not shown)-
 - We found that the following individuals were more likely to have a 30-day readmission than others, even after we controlled for other differences.
 - Younger adults (ages 19-25) compared to older adults.
 - Individuals making more visits to their primary care or other frontline physician.
 - And, those with higher levels of morbidity.
 - We found similar results when we looked at 30-day repeat ED visits.
 - As we saw for readmissions, younger adults, those with more visits to primary care and those with higher morbidity, were all more likely to have a 30-day repeat ED visit.
 - In addition, living in a rural area or having poorer continuity of care were also associated with a higher likelihood of returning to the ED for adults with **DD-plus**, again after the impact of other factors is controlled.

MORBIDITY→ An overall measure of how sick a person is.

Why do we look at this? In health care, high morbidity levels can signal a need for immediate or intensive treatment or a need for more coordinated care.

CONTINUITY OF CARE→

Defined as seeing the same provider over time.

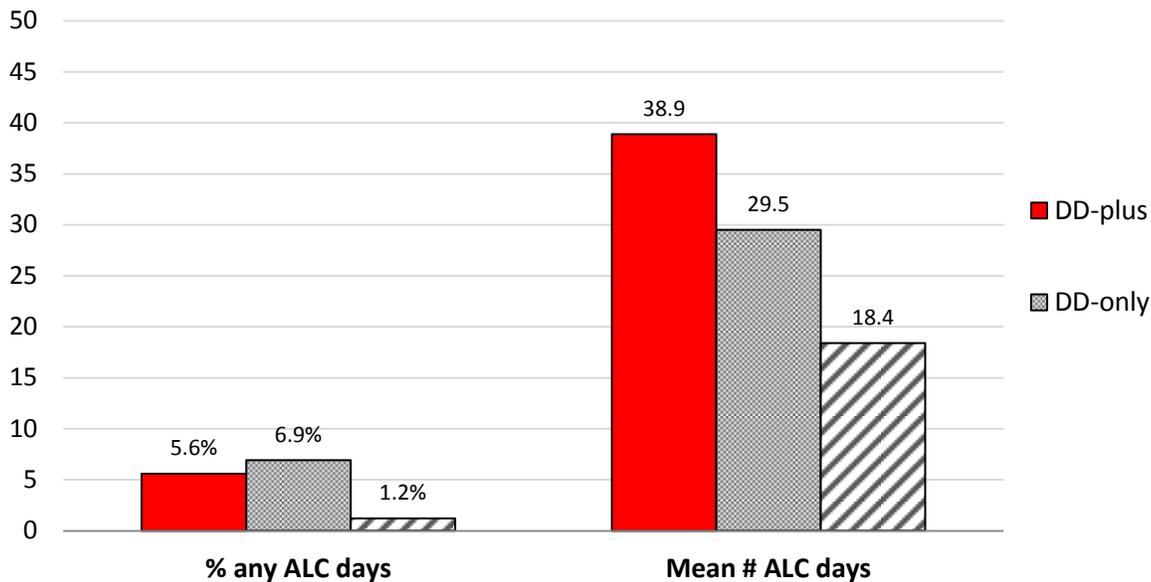
Why do we look at this?

Better continuity of care has been associated with better outcomes for patients.

Key finding

Adults with **DD-plus** are the most likely to have a 30-day readmission or a 30-day repeat ED visit compared with adults with **DD-only** and adults with **MI/A-only**, even when controlling for other factors.

Alternative Level of Care (ALC)



- Both **DD** groups were more likely than **adults without DD** to have at least one ALC day (5.6% and 6.9% vs. 1.2%).
 - Among those with at least one ALC day, the **DD-plus** group averaged nearly 5 and a half weeks (38.9 days) of ALC days compared to 1 month for **DD-only** and 2 and a half weeks for **adults without DD**.
 - To see whether this pattern held true even when other factors were controlled, the two **DD** groups were compared with adults with **MI/A-only** (See Appendix B).
 - Adults with **DD-plus** were 3.02 times more likely than adults with **MI/A-only** to experience ALC, even after controlling for other factors.
 - Interestingly, adults with **DD-only** had the highest rates. They were 3.4 times more likely to have any ALC than the **MI/A-only** comparison group.
 - Among the **DD-plus** (not shown), the only predictor of any ALC was age.
 - In the three oldest age groups (36-45, 46-55, and 56-65), individuals with **DD-plus** were between 2 and 4 times more likely than adults with **MI/A-only** to have any ALC days.
 - Again, the group with the highest rate was adults with **DD-only** who were between 3 and 5 times as likely to have at least 1 ALC day compared with adults with **MI/A-only**.

ALTERNATIVE LEVEL OF

CARE (ALC)→

This is when a patient is ready to be discharged but continues to stay in hospital because there is no appropriate place for them to go to receive the after-hospital care they need.

Why do we look at this?

An ALC designation means that patients who no longer need intensive care are preventing other patients from receiving the care they need ('bed blockers'). High ALC rates usually mean there is a lack of resources in other parts of the system leaving patients with nowhere else to go.

Key finding

After controlling for other factors, adults with **DD-plus** and **DD-only** were both more likely to have ALC days than adults with **MI/A-only**. Adults with **DD-only** were the most likely to have an ALC day and adults with **DD-plus** tended to have longer ALC stays.

Conclusion and Implications

Summary of findings

- While the **DD-plus group** are a small percentage of the population (0.36% of the Ontario population and less than half of adults with **DD**), they are considerably more disadvantaged in terms of their social determinants of health, physical health problems, and reuse of intensive health services.
- Previous work (Lunsky et al., 2013) showed that adults with **DD** live in the poorest neighbourhoods and have much higher rates of chronic disease, use of health services, and, in particular, reuse of health services compared to **adults without DD**.
- The current results show that these higher rates are largely due to the subgroup with **DD-plus**. When we separate out **DD-plus**, the **DD-only** group looks more similar to **adults without DD**.
- When we controlled for other factors that might contribute to higher rates of health care use, we found that the **DD** groups – and especially the **DD-plus** group – were still more likely to have problematic outcomes such as 30-day readmissions, repeat ED visits, and ALC days.
- In addition, our more detailed analyses show the importance of considering the specific impact of **addictions** among adults with **DD**. While the total number of individuals with both **DD and addictions** is small, we found that adults with **DD** are almost twice as likely to have an addiction as **adults without DD**. This has important implications for service providers in the **DD** sector and the addictions sector who are probably already seeing these individuals but not recognizing them.
- Most of those with **DD** and an addiction also have a mental illness and therefore are already in the priority population identified by the Ontario government under its dual diagnosis framework (Ministry of Health and Long-Term Care and Ministry of Community and Social Services, 2008).
- The subgroup of adults with **both MI/A** ('triple diagnosis') was in many ways the most complex. They have many more comorbidities and were the most frequent users and re-users of health services.

Moving forward

- We need to understand why the **DD-plus** population has such high rates of problematic outcomes, especially given that common explanations such as poor access to primary care, lower socioeconomic status, and poor continuity of care either do not apply or apply only partially. Our results suggest several key issues to consider.
- Smooth transitions from hospital to the community have been flagged as an important concern for all hospitalized individuals. Our analyses suggest that the **DD-plus** group's combination of needs may require intensive and specifically-tailored approaches to their discharge planning and post-discharge follow-up. A factor which we could not look at using the administrative data is what impact the availability (or non-availability) of community programs tailored to individuals with **DD-plus** has on their rates of readmission, repeat ED visits, and ALC days. Another factor to be considered is whether these individuals may choose not

to use such programs, even when they are available, because of other barriers (e.g., too far away, narrow eligibility criteria).

- The complexity of the **DD-plus** population documented in this report calls for closer attention as to whether these individuals are receiving the combination of mental health, addictions, physical health, and/or social services that they need. A particular challenge with this population is the necessity that these services, which are often delivered in ‘silos’, be coordinated in a fashion that can be easily accessed (e.g., in a one-stop shopping model) or easily navigated by individuals with **DD-plus** and their family and natural supports.
- While our findings show that high percentages of individuals with **DD** use the health care system, there is evidence that health care and social service providers do not recognize these individuals, see them in a negative light, and furthermore feel ill-equipped to interact with them (Lewis & Stenfert-Kroese, 2010; Lunsy, Gracey, & Gelfand, 2008). Similar attitudes among service providers towards individuals with addictions have also been reported (van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). The impact of such provider perceptions and attitudes on the quality of care received by individuals who have both conditions deserves further assessment and careful attention to how that impact might be mitigated.
- While the administrative data we used can provide some further insights in these key issues, they are not designed to collect some important information (for example, severity of DD, caregiver resources, client and provider attitudes). Future work will need to combine the information that can be provided by provincial administrative data with information from other sources, including qualitative data to better understand how to best serve this population.

References

- Butterill, D., Lin, E., Durbin, J., Lunskey, Y., Urbanoski, K., & Soberman, H. (September 2009). From hospital to home: The transitioning of Alternate Level of Care and long-stay mental health clients. Ministry of Health and Long-Term Care.
- Chan, B.T.B & Schultz, S.E. (2005). Supply and utilization of general practitioner and family physician services in Ontario. *ICES Investigative Report*. Toronto: Institute for Clinical Evaluative Sciences. Available at <http://www.ices.on.ca/Publications/Atlases-and-Reports/2005/Supply-and-utilization>
- Henry, D.A., Schultz, S.E., Glazier, R.H., Bhatia, R.S., Dalla, I.A., & Laupacis, A. (2012). Payments to Ontario physicians from Ministry of Health and Long-Term Care sources. *ICES Investigative Report*. Toronto: Institute for Clinical Evaluative Sciences. Available at <http://www.ices.on.ca/Publications/Atlases-and-Reports/2012/Payments-to-Ontario-Physicians>
- Lewis, S. & Stenfert-Kroese, B. (2010). An Investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, 23, 355–365. <http://doi.org/10.1111/j.1468-3148.2009.00542.x>
- Lin, E. & Balogh, R. (February 12, 2015). *Town Hall Presentation: Gaps in Health Care for Individuals with Developmental Disabilities and Mental Health or Addictions Issues*. <https://www.porticonetwork.ca/web/hcardd/dual-diagnosis/town-hall-dd-and-addiction>
- Lin E., Balogh R., Isaacs B., Ouellette-Kuntz H., Selick A., Wilton A.S., Cobigo V., & Lunskey Y. (2014). Strengths and limitations of health and disability support administrative databases for population-based health research in intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 11(4): 235–244.
- Lin, E., Balogh, R., McGarry, C., Selick, A., Dobranowski, K., Wilton, A.S., & Lunskey, Y. (submitted) Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): An Ontario population-based study. *BMJ Open*.
- Lunskey, Y., Gracey, C., & Gelfand, S. (2008). Emergency psychiatric services for individuals with intellectual disabilities: perspectives of hospital staff. *Intellectual and Developmental Disabilities*, 46(6), 446–455. <http://doi.org/10.1352/2008.46:446-455>
- Lunskey Y., Klein-Geltink J.E., Yates E.A., eds. (2013). *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*. Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health.
- Ministry of Health and Long-Term Care & Ministry of Community and Social Services. (2008). *Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis*. Available at http://www.mcscs.gov.on.ca/documents/en/mcss/publications/developmental/ds_reports/joint_policy_guideline.pdf
- Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, S.O. 2008, c. 14.

Van Boekel, L.C., Brouwers, E.P.M., van Weeghel, J, & Garretsen, H.F.L. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence*, 131: 23-35.

Glossary

30-day readmission: When an individual is admitted to hospital and then has another hospital admission within 30 days of discharge from the first admission.

30-day repeat ED visit: When an individual visits the emergency department (ED) and then returns (unplanned) within 30 days of being discharged from the first ED visit.

Adults-without-DD: A random sample of all Ontarians (18-64 years old) without **DD**.

Alternate level of care (ALC): When a patient is ready to be discharged but continues to stay in hospital because there is no appropriate place for them to go to receive the after-hospital care they need. In this report, we have defined ALC using the method described in Butterill, et al., 2009.

Continuity of care: Defined as seeing the same provider over time.

DD-plus: Persons with DD with mental illness and/or addiction.

DD-only: Persons with DD without mental illness or addiction.

DD-plus (only MI): DD plus a mental illness only.

DD-plus (only A): DD plus addiction only.

DD-plus (both MI/A): DD plus both a mental illness and an addiction.

MI/A-only: The subgroup of **Adults without DD** with a mental illness and/or addiction.

Morbidity: An overall measure of how sick a person is, usually based on how many illnesses or disabilities they have or how intensively they use health care services.

Physician visit: Visits to an Ontario physician which are either directly or 'shadow' billed to the Ontario Health Insurance Plan (OHIP).

Appendix A: Mental Illness and Addiction (MI/A)

Diagnostic Codes

Category	Coding system: Label	H-CARDD (mental health definition)
Psychotic Disorders	OHIP	
	Schizophrenia	295
	Paranoid states	297
	Other psychoses	298
	Childhood psychoses (e.g., autism) - 299	EXCLUDED
	ICD-9	
	Schizophrenic disorders	295
	Delusional disorders	297
	Other organic psychoses	298
	ICD-10	
	Schizophrenia, schizotypal, delusional, other psychotic, schizoaffective,	F2
	DSM-IV	
	Psychotic disorders due to medical conditions	293.81 , 293.82 (Note: 298.83 is coded under 'Other')
	Schizophrenia, schizophreniform, schizoaffective	295 (inclusive)
	Delusional, shared psychotic disorder	297 (inclusive)
Brief and psychotic disorders	298 (inclusive)	
OMHRS provision diagnosis (use only if no DSM-IV diagnosis)		
DSM: Schizophrenia, other psychotic disorder	Q1E = 1	
Non-psychotic (non-psychotic, continued)	OHIP	
	Senile/presenile dementia	290
	Manic depressive psychosis, involuntal melancholia	296
	Anxiety neuroses, reactive depression, etc.	300
	Personality disorders	301
	Sexual deviations	302
	Psychosomatic disturbances	306
	Habit spasms, tics, stuttering, tension headaches, anorexia nervosa, sleep disorders, enuresis	307
	Adjustment reaction	309
	Depressive or other non-psychotic disorders, nec	311
	Behaviour disorders of childhood and adolescence*	313
	Hyperkinetic syndrome of childhood*	314
	Specific delays in development (e.g., dyslexia, ..motor retardation)	EXCLUDED
	Mental retardation (319)	EXCLUDED
	ICD-9	
	Dementias	290
	Other transient disorders (e.g., delirium)	293
Persistent mental illnesses due to other conditions (e.g.	294	

Category	Coding system: Label	H-CARDD (mental health definition)	
(non-psychotic, continued)	amnesic disorders, Alzheimer's)		
	Episodic mood disorders	296	
	Anxiety states also including Dissociative, conversion, and factitious disorders (300.1) Phobic disorders (300.2) OCD (300.3) Dysthymia (300.4) (note; this is a mood disorder) Neurasthenia, derealization, hypochondriasis, somatoform, unspecified non-psychotic (300.5-300.9)	300	
	Personality disorders	301	
	Sex and gender-related disorders	302	
	Psychogenic malfxn from mental factors	306	
	Specific sx, NEC (e.g., stuttering, eating disorders, tics, etc.)	307	
	Acute stress reaction	308	
	Adjustment reaction	309	
	Non-psychotic conditions due to brain damage	310	
	Depressive disorder, nec	311	
	Disturbance of conduct*	312	
	Disturbance of emotions specific to childhood*	313	
	Hyperkinetic syndrome of childhood (e.g., ADD)*	314	
	Specific delays in development (e.g., reading)	EXCLUDED	
	Psychic factors associated with diseases classified elsewhere	316	
	ICD-10		
	Dementia (Alzheimer's, vascular, other diseases, unspecified) Organic amnesic syndrome Delirium Other mental and personality disorders due to brain damage, disease Unspecified organic disorder	F0 (includes F00-F09)	
	Manic, bipolar, depressive disease, cyclothymia	F3	
	Eating disorders, nonorganic sleep, sexual dysfunction, associated with puerperium, etc.	F50, F51, F52, F53	
	Phobias, panic, GAD	F40, F41	
	OCD	F42	
	Stress reaction, PTSD, etc. (includes adjustment disorder – F43.2)	F43	
	Dissociative, somatoform, Other (neurasthenia, depersonalization)	F44, F45, F46, F48	
	Psychological and behavioural factors associated with disorders of diseases classified elsewhere; abuse of non-dependence-producing substances; unspecified behavioural syndromes	F54, F55, F59	
	Personality disorders, mixed personality disorders, enduring personality change	F60, F61, F62	
	Habit and impulse disorders	F63	
	Gender identity disorders, disorders of sexual preference, disorders associated with sexual development and orientation	F64, F65, F66	
	Other disorders of adult personality and behavior (including Munchausen's), Unspecified	F68, F69	

Category	Coding system: Label	H-CARDD (mental health definition)
	Mental retardation (F7) Disorders of psychological development, scholastic skills, pervasive developmental disorders, (F8)	EXCLUDED
	Hyperkinetic, conduct disorders, separation anxiety, attachment disorders, tic disorders, stammering*	F90, F91, F92, F93, F94, F95, F98
	Mental disorder, NOS	F99
DSM-IV		
	Mood disorder, NOS	206.90
	Dementias	290
	Mental conditions due to medical conditions	293 (but NOT 293.81, .82)
	Dementia/Amnestic disorders due to medical conditions	294
	Major depressive, Bipolar disorder	296 (296.00 to 296.89)
	Anxiety disorders as well as: Conversion disorders (300.11) Dissociative (300.12 through 300.15) Factitious (300.15, 300.19) Dysthymic disorder (300.4) Depersonalization, body dismorphic, hypochondriasis, somatoform (300.6, 300.7, 300.81) Unspecified mental disorder (300.9)	300
	Cyclothymic disorder	301.13
	Personality disorders	301 Except 301.13
	Sexual dysfunction, pedophilia, paraphilia, etc.	302
	Vaginismus (not due to a general medical condition)	306
	Eating disorders, tic disorder, Tourette's, insomnia, sleep disorders	307
	Acute stress disorder	308.3
	Adjustment disorders as well as PTSD (309.81)	309
	Personality change due to medical condition	310 (inclusive)
	Depressive disorder, nos	311
	Impulse control disorders (e.g., kleptomania, conduct disorder, etc.)*	312
	Other disorders usually dxed in infancy, etc. (e.g., selective mutism, oppositional defiant disorder, etc.)*	313
	ADHD*	314
	Psychological factor affecting a medical condition	316
	Mental retardation (317-319)	EXCLUDED
	All codes after 319	EXCLUDED
OMHRS provision diagnosis (use only if no DSM-IV diagnosis)		
	DSM: various	If 1 in (Q1B, Q1C, Q1F to Q1P)

Substance-related, addictive disorders	OHIP	
	Alcoholic psychosis, DTs, Korsakov's	291
	Drug psychosis	292
	Alcoholism; alcohol intoxication/dependence	303
	Drug dependence, drug addiction	304
	Drug, tobacco abuse	305
	ICD-9	
	Alcohol, drug-induced mental disorders	291, 292
	Alcohol, drug dependence	303, 304
	Non-dependent drug abuse	305
	ICD-10	
	Mental disorders due to psychoactive substance use	F1
	DSM-IV	
	Alcohol-related/induced conditions	291
	Other substance-related withdrawal (amphetamines, opioids, sedatives, etc.)	292
	Alcohol intoxication, dependence	303 (inclusive)
	Other substance dependence, abuse	304 305
	OMHRS provision diagnosis (use only if no DSM-IV diagnosis)	
	DSM: Substance-related disorder	Q1D = 1

Appendix B: Across-group Multivariate Analysis Results

Table 1: Odds ratios of having any of three problematic service use outcomes for Ontario adults with **DD-plus** or **DD-only** compared to Ontario adults with **MI/A-only***

Diagnostic Group	<i>Problematic Service Use Outcome**</i>					
	30-day readmission Total n= 4,837		30-day repeat ED visit Total n=46,751		Any ALC Total n=1,610	
	n (%)	Multivariate odds ratio*** (95% CI)	n (%)	Multivariate odds ratio*** (95% CI)	n (%)	Multivariate odds ratio*** (95% CI)
DD-plus	585 (12.1)	1.66 (1.51-1.83)	3,275 (7.0)	1.37 (1.32-1.43)	284 (17.6)	3.02 (2.62-3.47)
DD-only	229 (4.7)	1.27 (1.10-1.47)	1,944 (4.2)	1.14 (1.09-1.21)	186 (11.6)	3.42 (2.88-4.05)
MI/H-only (Reference group)	4,023 (83.2)	1.00	41,532 (88.8)	1.00	1,140 (70.8)	1.00

BOLD = statistically different from Reference group

* DD-plus: developmental disability plus psychiatric and/or substance/addictive disorder
 DD-only: developmental disability, no psychiatric and/or substance/addictive disorder
 MHA-only: psychiatric and/or substance/addictive disorder, no developmental disability

** Outcome measured using Fiscal Year 2010 data.

*** Controlling for age, sex, region (urban/rural), neighbourhood income, continuity of care, number of visits to primary care physician or psychiatrist, morbidity level, LHIN beds per 100 population, primary care physician supply, psychiatrist supply

- The objective of the analyses summarized in Table 1 was to determine whether having either **DD-plus** or **DD-only** contributed significantly to a person experiencing one of three problematic service use outcomes – namely, being readmitted to hospital within 30 days after a previous hospital admission, returning to the ED within 30 days of a previous ED visit, and remaining in hospital even though the person’s physician has judged that he/she is ready to be discharged. These three system outcomes are labeled **30-day readmission**, **30-day repeat ED visit**, and **any ALC** in the table above. **ALC** stands for ‘alternate level of care’.
- However, there are other factors such as age, morbidity level, or hospital bed availability that may also affect these outcomes. Consequently, these and other factors which might be influential have been statistically controlled using multiple regression analysis.
- For these regression analyses, we chose to compare the two **DD** groups with adults who have mental health and/or addictions problems (**MHA-only**) rather with than the **Adults without DD** group that was used in the graphs in the main part of this report. The reason is that **Adults without DD**, as a group, are likely to be less

ill (e.g., many will have few or even no health or mental health problems) and therefore would ‘stack’ the comparisons with the two **DD** groups.

- Even after controlling for these other factors, having a **DD** (either **DD-plus** or **DD-only**) was still significantly related to all three outcomes. Compared to the **MHA-only** group, the two **DD** groups were between 1.27 and 1.66 times more likely to be readmitted to hospital within 30 days, between 1.14 and 1.37 times more likely to return to the ED within 30 days, and between 3.02 and 3.42 times more likely to have one or more ALC days.
- When the **DD-plus** and **DD-only** groups are compared with each other, the **DD-plus** group is statistically more likely to have repeat hospitalizations and repeat ED visits (specifically, the CIs for the two groups do not overlap – e.g., for 30-day readmission, 1.51-1.83 does not overlap with 1.10-1.47).
- The **DD-only** group is more likely to have at least one ALC day, but the CIs overlap (see Tips for reading Table 1).

Tips for reading Table 1:

- For each outcome, the first column provides the number and percent of individuals who have that outcome and who are in each Diagnostic Group.
- The second column shows the adjusted odds ratio when compared to the Reference (or comparison) Group. The closer the odds ratio is to ‘1’, the less likely it is that the two groups are different from each other.
- **BOLDED** odds ratios are statistically different from the Reference Group.
- If the 95% confidence intervals (CIs) for two odds ratios do not overlap, the two Diagnostic Groups are considered statistically different from each other. If the CIs do overlap, the groups may still be statistically different. However, there is also the chance that they are not. The larger the overlap between their two CIs, the more likely it is that they are not different.



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