



# 2020/2021 MENTAL HEALTH INVESTMENTS INITIATIVE

Initiative: Expanding Support Services in Existing Navigation and Case Management  
Developmental Services Programs to Improve the Mental Health of People with Developmental  
Disabilities during COVID-19

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## Introduction

People with a Dual Diagnosis (DD) of a developmental disability and mental health often struggle to navigate systems that are meant to support them. Inconsistent linkages or pathways between Developmental Services (DS) and Mental Health (MH) services complicate the navigation between these sectors for people with developmental disabilities and mental health challenges or crises. Research in Ontario shows that these complicated and inconsistent pathways result in people with a DD being more likely than people without a DD to visit an Emergency Department (ED) for psychiatric reasons (Durbin, Balogh, Lin, Wilton, & Lunsky, 2018). Despite EDs being largely unhelpful in supporting people with a DD in mental health, multiple factors influence the decision for someone with a DD to visit an ED for psychiatric support (Lunsky, Balogh, & Cairney, 2012).

The current research project aims to explore this gap in service that leads people with a DD to access unhelpful mental health support in EDs. We hope to discover the programs, supports and resources in Waterloo Region that are available to people with a DD to address mental health challenges and prevent crisis. We would like to learn about successful pathways or linkages between the Developmental Services (DS) and Mental Health (MH) sectors, and how these pathways can be duplicated for other people with a DD to avoid use of EDs for psychiatric purposes. We hope to understand the service gaps and challenges for people with a DD attempting to access both DS and MH sectors, and discuss how those challenges can be addressed. We would like to understand services gaps and linkages in both urban and rural areas of the Waterloo Region. Understanding these successful linkages in service will allow us to create a “road map” or a systems pathway to Mental Health Resources in Waterloo Region that can be accessed by DS organizations. It is felt that this research is a first step in providing

organizations with more information on DS and MH services. It validates the obvious need for continued MH and DS collaborations with reciprocal education being imperative.

## Background

In their research on Emergency Department (ED) use, Durbin, Balogh, Lin, Wilton, & Lunsky (2018) found that adults with Intellectual and Developmental Disabilities (IDD) visited the ED for psychiatric reasons (43.8%) almost double the amount of times adults without an IDD visited the ED for psychiatric reasons (24.7%). This information highlights the impacts that challenges to accessing community based mental health care have on people with a DD; they must utilize EDs for mental healthcare.

Additionally, in urban centers in Ontario, Canada, accessing community based mental health care is challenging for someone with DD (Lunsky, Balogh, & Cairney, 2012). Without established mental health supports, it seems the most feasible option for care is a visit to an ED (Lunsky et al., 2012). Lunsky et al. (2012) touch on the widespread consensus in the DD and MH fields that ED use for psychiatric crises is at the best of times, unhelpful to individuals and their families and is also costly to the system. However, of the participants in the Lunsky et al. (2012) study who were visiting the ED for psychiatric reasons, 74% had at least one previous visit to an ED.

This suggests the mental health challenges that lead a person to go to the ED are not being resolved in their first visit. Without a crises plan and strategies in place people with DD may consider an ED the best way to deal with their mental health crises (Lunsky et al., 2012). These findings show an overwhelming need to support people with a DD to access mental health care and decrease their use of EDs for psychiatric reasons. DD literature has highlighted that

linkages into the MH sector for people with DD need to be improved; too many people with a DD are utilizing EDs for mental health support. Our next steps in the community are to decrease utilization of EDs for psychiatric reasons, and increase the linkages and pathways from the DS sector into the MH sector.

To add to the background of literature, personal experiences within Elmira District Community Living are that linkages between the DS sector and MH sectors are based on relationships and personal connections. It is felt that the best way to access MH supports and resources is to know someone in the system and work that relationship. If this personal connection between the two sectors is lost, a person with DD must navigate the two systems, and try to create a link with MH services on their own.

The literature and personal experiences indicate that people with DD are using EDs for mental health care. This may be due to the lack of MH care options, few linkages from DS into MH systems, and lack of systemic support to navigate the MH sector as a person with a DD. The aim of this project is to understand the service gaps and challenges for people with Dual Diagnosis attempting to access both DS and MH sectors and create a “road map” or a systems pathway to Mental Health Resources in Waterloo Region that can be accessed by DS organizations, people with a DD, and families of people with a DD.

## Methodology

### Participant recruitment

The intended sample of the study was 13 people in total; four DS stakeholders, three MH stakeholders and six people with a DD. We were able to interview 12 people total. Four DS stakeholders, one from each of the cities Kitchener, Waterloo, Cambridge and Elmira. Despite

recruitment efforts, we were only able to speak with two MH stakeholders. In the planning stages, we had not considered speaking with advocates, only six people with a DD for first-hand experience. Two DS stakeholders referred the investigators to two advocates who could speak on behalf of their non-verbal family member or person they support. The investigators felt it was valuable to hear from advocates and people with a DD who may not always get a chance to share their stories, successes, and challenges. We ended up speaking with three advocates for people with a DD. The last and important group of people were three people with a DD who shared their experiences with MH services. In summary; four DS stakeholders, two MH stakeholders, three advocates for people with a DD, and three people with a DD were interviewed.

To get into contact with the intended sample, multiple methods of recruitment were used. The six DS and MH stakeholders were contacted through personal connections with community living and mental health agencies. Investigators reached out to DS and MH stakeholders to participate in interviews, or ask them to refer us to people who may be interested in participating.

The advocates were also contacted in multiple ways. Two advocates were connected to this project through two of the DS stakeholder participants. The last advocate was connected through the supervisor of the study. Recruitment for people with a DD recruitment involved providing a poster with details of the research and contact information to the primary investigator was to multiple independent living community bulletin boards. The poster did not generate any responses, so one person with a DD was connected through the supervisor of the study, and two were referred by a DS stakeholder participant.

The Covid-19 Pandemic and virtual world we must live in, unfortunately, limited the accessibility options for interviews with people with a DD. The best effort was made to accommodate people through phone, video chat, texting, or written interviews.

## Stakeholder data collection

After a DS or MH stakeholder participant agreed to take part in a virtual interview, I provided the information letter and addressed any questions or concerns the participant had. The 2020/21 Covid-19 Global Pandemic requires social distancing and limited contact with others. As a result, the interviews took place via confidential video chat using the Zoom platform over the telephone. At the beginning of the interview the details of the study were outlined, and the verbal consent form was presented and signed by the investigator. The interviews were audio recorded for data analysis, one interview was over the phone and responses were written rather than recorded. The stakeholder interview question list is attached in Appendix A (p. 22).

One of the DS stakeholder interviews consisted of written interview questions and answers. In this case, the DS stakeholder was the supervisor of this project. This investigator has a valuable perspective on this research topic as she works for Elmira District Community Living, a rural agency that represents different experiences for people with a DD compared to those living in larger city areas of the Region. This stakeholder is the main contact for DD and MH in their rural agency, and to avoid any conflict of interest or leading the interview the investigators decided to conduct a written interview. The rural perspective of direct linkages between DS and MH services is a key piece of knowledge to this research project.

## Participants with a DD and advocate data collection

For participants with a DD, I was first connected with a staff who supported each participant, and sent a Zoom link and information about the project to the staff or participant email. Once on the Zoom call, I introduced myself and the study and answered any questions they had. I received verbal consent to continue with the interview and record audio for data

analysis. Interviews lasted up to 15 minutes for participants with a DD and participants were sent a \$50 Amazon gift card for their time. The person with a DD interview question list is attached in Appendix B (p. 23).

For advocates, once connected I sent them the information letter and Zoom link. Once on the Zoom call we went over the verbal consent form as well as the details of the study and had time for any questions. The interview question list is attached in Appendix A (p. 22). The people the advocates were speaking on behalf of were sent a \$50 Amazon gift card for allowing their story to be shared for this project.

## Data analysis

After interviews took place, I listened to the recording and generated qualitative codes for main talking points of the interview. I then organised these codes into meaningful themes for each group of participants (themes for; DS stakeholders, MH stakeholders, people with DD, and advocates). These themes included barriers and challenges for people with DD accessing MH supports, and direct linkages from DS to MH services.

## Results

### Systems pathway

The supports and direct linkages that were mentioned across interviews were compiled into a systems pathway or mental health road map that can be seen in Appendix C. There are two sections to this systems pathway; the first is pathways into mental health supports. This section is an outline of the services and connections that people have used and had success with in the past. These are all places one could reach out to for support with dual diagnosis. The second section is

titled 'what may help'. These are pieces of advice from interviewees that may be worth trying or considering while navigating between DS and MH services.

### Firsthand perspective

Any direct linkages, contacts or services provided by advocates DS stakeholders or MH stakeholders are included in the systems pathway in Appendix C (p.24). We got a firsthand perspective for this project by interviewing people who have a dual diagnosis (DD). These interviewees were asked about what has helped with their mental health and how they were connected with those helpful supports and services. A theme across participants with a DD was the benefit of a balance between Psychiatry and counselling. Psychiatry was voiced as important due to the access to medication that had a positive impact on people's lives and emotion regulation. It was also important for people with a DD to have counselling treatments such as DBT and talk about their mental health. Participants with a DD felt they were doing their best when they had a good balance between psychiatry, medication and counselling.

Other supports to mental health included day programs, being out in the community, and practicing hobbies. Support staff and managers were also seen as very important for support with mental health because they know the person well, how to support the person with de-escalation, and "figure out my feelings" as quoted from a participant with a DD.

Participants with a DD suggested that other people with DD look around and get as much support as possible as a good support circle is important for mental health. The more support you get the better, so try new things! When asked about challenges to getting help with their mental health the participants with a DD did not have anything to report at the time of the interview.

## Advocate perspectives

This section will discuss the supports and barriers advocates experienced supporting people with a DD access MH supports. To begin with supports, advocates found family doctors to be very involved in care and helpful in referrals and connecting people with a DD to psychiatrists and other services. The next and equally as important person to have involved in care is an involved psychiatrist. A connection with an involved psychiatrist can not only help with medication, but can also have a trickle-down effect to get the person connected to more services. In other words, once a people with a DD has a psychiatrist they are able to access more services in the community.

Advocates spoke about the importance of continuity of care. If a person is diagnosed and connected with some services in childhood they are able to continue with some supports into adulthood. As such, trying to get connected with services as early as possible in a person's life is important. It was mentioned that it is often hard to provide continuation of care due to waitlists and access to care. Other supports for advocates and people with a DD outside of systems and services included walks and individual time with the person, and parent support groups for a family advocate.

One of the major barriers to supporting people with a DD in accessing mental health supports was the amount of specialized MH services available for people with DD. Considering the importance of psychiatry to a person's care, there is an alarming lack of psychiatrists to support the community. Waitlists are long and people are not often able to access critical support for years. It was one advocate's experience that a psychiatrist the person they were supporting

was connected to turned to medication as a first resort and did not seem to have time for this person with a DD. The advocate said, unfortunately, there are not many other people to turn to for help. Due to a lack of specialized services and long waitlists people with DD are often referred to the emergency room or police to get ‘in the moment’ support. Advocates also spoke about the time and effort it takes to navigate systems meant to support people with DD, one person described it as a hassle and frustrating. A family advocate explained that they did a lot of advocacy work too because case managers were overburdened with the system.

There was also a discussion around the barriers of a reactive system. It was felt that if preventative supports were in place for people with DD, they may need much less support down the road. Unfortunately, the lack of specialized care in the community results in a systems that only has the capacity to be reactive. One advocate pointed out that mental health often has patterns, like age of onset. For example, MH can surface during puberty. A preventative system could speak with people supported through DS around this age to discover if they are experiencing struggles and connect them with services at an early age rather than years later when things may reach a crises point.

Advocates explained that in order for people with dual diagnosis to get the support they need, there needs to be different levels of collaboration. The first level is collaboration amongst services, a person with DD needs a multidisciplinary team of therapists, counsellors, and psychiatrists to name a few. It is key that these services work together and try different thing to support people with a DD. Important services and people to include in this multidisciplinary team are; psychiatry, doctor, health therapist, neurologist, dietician, behavioural therapist, 1:1 support, sensory therapy occupational therapy or Applied Behaviour Analysis (ABA) therapists.

The next level of communication is between services and frontline staff and family. Frontline staff and family know the individual and often record a lot of information about them. It is important that services collaborate and listen to these support people to learn about the person with DD and their MH.

A question in the advocate interviews was what advice they may have for people with a DD or service providers. To people with a DD: do not necessarily expect anything to happen overnight. With this, it is important for frontline staff to be honest about care and if a service is not working out or taking a long time, but be ready to try something else. Give people with a DD hope and let them know you are not going to stop there.

Advice for service providers is to take detailed records, as the more information you have on paper more likely will get access to services. Push hard, and if you can't find support here, look somewhere else, there's always a door that will open, keep trying.

To psychiatrists the advice was to be involved and ask pertinent questions, consider treatment beyond medication. It was a hope that all Psychiatrists could get training in DD so there are more people better able to support the DD population.

Advice to parents was to reconnect with offices once a month or so to ensure they are still on the waitlist as unfortunately people can get lost on waitlists. It's okay to call and remind the service their support is still needed. It was also suggested that parents seek out formal support groups for their own support, and informally connect with other parents and learn about services they may not have heard of before.

[Developmental Services \(DS\) stakeholder perspective](#)

Stakeholders who work in DS expressed multiple supports and challenges to accessing MH services for people they support with DD. One of the largest supports that was mentioned was having a diagnosis. A diagnosis helps people get connected with other services, medication, gives a clear way forward and many programs require a diagnosis for access. Transition from youth to adult services can also be helped with a diagnosis.

Doctors came up as powerful allies to people with DD as a general practitioner can be a portal to other services through referrals. Doctors are able to refer to psychiatrists for diagnosis as well as other services. A referral to MH services from a doctor can help someone get through the door faster than a waitlist can. Besides a doctor, self referral agencies can also be helpful and people have been quickly connected to psychiatrists through this pathway in the past. Self referral agencies could include WayPoint, St Jo's, or Here 24/7.

In addition to more formal referrals, DS stakeholders have found that building relationships and leveraging those connections is helpful in supporting people with DD access MH supports. Networking can help move a persons treatment forward, and favours and relationships can move quicker than a waitlist. It was stated that people will help you navigate and direct you if they can, so it's important to make and maintain any connections you get so you could refer to them in the future for support. It was explained that connections often go both ways between MH and DS sectors, often referring people with a DD to each other. Relationships also go beyond these two sectors as it's important to have relationships with courts, substance use services or other silos.

A circle of care is considerably helpful for people with DD. One DS stakeholder said that "mental health stability can be most successful when the rest of someone's life is stable. Taking medication consistently once the correct combination is figured out, stable housing, access to

healthy food, support around hygiene, opportunities to be connected to people and activities all help to anchor someone”. Another advocate described the success a person had once connecting them with a circle of psychiatrists, counsellors and group activities through Peel Behaviour Services. A third advocate encouraged people to reach out to the DSO for a list of professionals who can provide support, and to get the school board involved if possible for introductions to service gatekeepers. Important people and services to involve in care include; the person with a DD, family, frontline staff, house manager, court system, community partners, Grand River Hospital, Freeport Hospital, Central West Specialized Developmental Services (CWSDS), police, doctor or dietician.

DS stakeholders also discussed the barriers they have experienced while supporting people with a DD access MH supports. One of the major barriers is the amount of time and effort it often takes to get MH support. People with a DD need a strong support system but for the individual, their family or staff it seems like a “fight” to get services. Sometimes strong advocacy does not lead to the services needed. Waitlists into services are also a barrier as sometimes it takes years for a person to get the crucial support they need. Overall, the system was described as challenging and complicated, and support people need to know the system and have connections to referrals to get into MH supports. Due to this complicated system people often get bounced in between services and can end up getting lost in the system. One DS stakeholder expressed that people get lost because “there is no where exactly meant for them, is it law, MH, DS? So they almost end up with nothing”.

It also seems to be more difficult to get support for people with a DD with a complex situation compared to people who do not have a dual diagnosis. One of the barriers for people with DD is often communication; people who are verbal can often get better supports than those

who are non-verbal according to the DS stakeholders. With communication barriers, a person cannot speak for themselves, or about how a medication is making them feel. On top of communication, the physically accessing MH supports can be a barrier for people with a more complex DD. If someone is typically restrained for travel, or experiences anxiety about leaving the home, one stakeholder asked; ‘how are they supposed to be observed’?

As the interviewer, I also made an observation during interviews which was the complexity of a person’s situation seemed to dictate how complex accessing supports would be. The people with DD I interviewed who were living independently and were verbal seemed to follow a path that involved front line staff reaching out to a counselling agency, and the counsellor then connecting them with a psychiatrist. With these connections they felt a balance with counselling and medication. Advocates I spoke to who were representing more ‘complex’ people with a DD seemed to have a more complicated road ahead to access a psychiatrist or other supports who could help with mental health.

DS stakeholders explained that much of the reason it is so hard to advocate for and connect with MH supports, is because there is simply not enough specialized supports for those who need it. It was mentioned that Kitchener-Waterloo is a ‘service desert’, and there seems to be even less supports for people in Cambridge. Since there are not enough specialized supports like counselling or psychiatrists, people with DD either do not get connected with one, are turned away for being ‘too complex’, or are connected with people who are not trained in DD. Having training and being comfortable working with people with DD is crucial as people can exhibit ‘non-conventional symptoms’ and it is not always the same as working with someone without a DD. One DS stakeholder explained that we are at the point where we cannot enrich services with the same providers because they are already busy, what is needed is more providers and funding.

DS stakeholders also explained that stigma towards people with DD is a barrier to them receiving MH supports. The stigma against the person with a DD involved labeling someone as having ‘behaviours’ or being ‘attention seeking’, and not addressing the emotions that are driving these ‘behaviours’. This stigma the people are not experiencing MH but are just having behaviours makes it extremely hard for them to access the support they need. Due to this stigma, frontline workers and people with a DD often have the burden of proving the person is experiencing MH struggles because they need to ‘develop credibility in the face of a professional that may be skeptical’. This proof comes in the form of documentation, detailed data collection and notes. It was also explained that there is some stigma with staff, as people with a DD can be seen as already supported by DS, so frontline staff must only be looking for more help because they are tired or burnt out.

The last barrier that was able to be discussed in the interviews included funding for MH services. Funding for MH can be a barrier unless provided by Ontario Disability Support Program (ODSP), but even then ODSP does not offset everything, or is only funded for limited sessions. It was suggested that more funding be available for these situations.

DS stakeholders shared many suggestions on what needs to happen in order to better support people with DD access MH support. The first suggestion was that there needs to be more psychiatrists with a speciality in DD. In order for people with DD to get the support they need, there needs to be people to provide that support. On top of that, there should be ‘capacity building for local physicians to understand how MH can present differently in someone with DD’. With this education, more physicians would be equipped to support people with DD, and know when to refer someone to MH services. Education on DD should continue to frontline staff in both DS and the MH sector. Education could address how to support people with a DD, and

also make clear what services and supports each sector offers. A relationship between sectors, built off understanding each other, DD, and efforts to bridge the gap between services could address stigmas and connect people with a DD to more services.

The next suggestions involve the system itself. DS stakeholders said a single access point is crucial because if the person with a DD doesn't have a strong or knowledgeable advocate, they will not find all the services. Someone with a strong advocate could be on six waitlists where someone without an advocate could be on none. A single access point would introduce everyone to these supports. This access point could provide navigation for connecting people with a DD to services.

The final suggestion that will be mentioned here is proactive service; prevention is key. If supports are in place people may not even enter crises stages. When all care and supports are put in place early, people may not need such complex support in the future. It was suggested that the process of applying to the DSO involve a MH assessment of diagnosis right away, instead of waiting until someone shows symptoms down the line. Of course, not everyone who enters the DSO and had a MH assessment would have a diagnosis, but it may be possible that some people would be diagnosed earlier and set them on a road of prevention rather than reaction.

The final questions asked to DS stakeholders was what advice they have for people with a DD and services providers trying to access MH support. Service providers must be prepared, knowledgeable and keep pushing. One DS stakeholder spoke about leveraging connections and said 'While you are going through the process get names, contact information and document the process. That way you have a roadmap for the next time through.' Another point of advice was to have a strong MH maintenance plan for when a person starts to have difficulty, and to communicate that plan with everyone so treatment is consistent. Finally, a family doctor can be a

very powerful ally, so try to connect and do as much work as possible with them and get referrals.

### Mental Health (MH) stakeholder perspective

The MH stakeholders identified the main pathway into MH services and other supports they have experienced. The main pathways into MH that were discussed was being registered with Developmental Services Ontario (DSO), being connected with a Behavior Therapist, and having an IQ score below 70. People registered with the DSO can access MH supports at the GRH DD clinic. Another pathway to MH supports is through the Sunbeam Developmental Resource Center. Doctors can also participate in outpatient services. For crisis or immediate services, it was suggested to connect with the IMPACT team through Here 24/7 which is a Police and Crisis Team that arrive with a knowledge of MH systems and support to help people in crises connect with the support they need.

One of the major barriers to people with DD accessing MH services that was discussed was the lack of funding and services. DD is a specialty and there are only a few doctors with the training, so services need to broaden in order to support more people and decrease waitlist times. Another barrier to supporting people with DD in MH is that there is not a complete understanding in the MH world of everything that is in the DS world. Over the years there has been more of a need to work together, so there is a need to collaborate and understand each other.

The next barrier that was discussed was the layer of complexity that substance use, brain injury and limited housing add to accessing MH services. MH stakeholders explained that substance use is showing up more with people with DD which complicates treatment, and DD recovery is more specialized than general recovery. Additionally, it can be difficult to find a good fit with a Psychiatrist as many services require abstinence from substance use before they provide treatment. Unfortunately, it can be very difficult and take a long time for people to be completely abstinent. Substance use is a significant layer of complexity that can complicate access to MH support.

Brain injury is an emerging focus in the MH field, and one stakeholder explained that this adds a layer of complication because more people are involved in the care circle and MH can be impacted in many different ways by a brain injury. People may also not realize they have a brain injury, so could be dealing with its impacts without knowing. The final layer of complexity that was discussed with MH stakeholders was the lack of housing for people with DD. People with DD are often in inpatient care for longer than they need to be, merely because there is no proper housing and no where else for them to go.

Some of the reason for lack of housing is the long-term need of people with a DD. One stakeholder said that housing helps immensely with stability and treatment, but the pendulum was swung so far away from institutionalization that people are expected to live in community and have no supports. People do well in structured environments, but institutions have a bad connotation even though these services have come a long way. It was said that there should be a balance between DS and MH sectors in housing so people can get supportive DS housing with specialized and trained staff.

The last question that was asked to MH stakeholders was what needs to happen to better support people with DD access MH supports. The major suggestion was that more services and funding be given to MH and DS services. The next was working on improving community understanding and education in DD; public opinion can influence if services like safe injection sites are implemented, and where funding goes amongst other impacts on MH. It was considered important for both sides, DS and MH to collaborate, and get involved with people early on as early involvement will help in the long run. It was noted that there are a lot of similarities between geriatric doctors and DD doctors; one geriatric doctor is practicing with people with DD in the Region of Waterloo and it is going well. Services should be creative and marry services together like this to create the help that is needed because there is still not enough. The final suggestion was more collaboration between DS and MH services in housing. DS could provide more in-patient DD housing with treatment and specialized staff for the maintenance of MH treatments and stability over time.

## Conclusion

To conclude, hearing from people with a DD, advocates, and stakeholders has reinforced that there are many amazing supports, relationships, and work that is being done to support people with DD access MH supports. At the same time, there are long and difficult battles that often need to be overcome to access this MH support. This project has allowed exploration of the supports and barriers to accessing MH, and the creation of a Mental Health Systems Pathway for Waterloo Region. This systems pathway will hopefully act as a roadmap for those attempting to navigate complex MH and DS systems.

A summary of important people and supports to have involved in a circle of care include; the person with a DD, family, frontline staff, house manager, psychiatrist, doctor, health therapist, neurologist, dietician, behavioural therapist, 1:1 support, sensory therapy, occupational therapy, Applied Behaviour Analysis (ABA) therapists, court system, community partners, Grand River Hospital, Freeport Hospital, Central West Specialized Developmental Services (CWSDS), police, Brain Injury (BI) specialist, substance-use services.

The major recommendations from participants of this study involve;

- more funding for DS and MH sector
- more specialized services
- creative services to address a need not being met
- collaboration between MH and DS
- more DS housing
- capacity building for physicians
- single access point to services
- continuation of care from child to adulthood
- education for community and frontline staff in both sectors.

Future directions of projects meant to expand support services could work on improving or exploring these recommendations.

## References

- Durbin, A., Balogh, R., Lin, E., Wilton, A. S., & Lunskey, Y. (2018). Emergency department Use: COMMON Presenting issues and continuity of care for individuals with and without intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders, 48*(10), 3542-3550. doi:10.1007/s10803-018-3615-9
- Lunskey, Y., Balogh, R., & Cairney, J. (2012). Predictors of emergency Department visits by persons with intellectual DISABILITY experiencing a PSYCHIATRIC CRISIS. *Psychiatric Services, 63*(3), 287-290. doi:10.1176/appi.ps.201100124

## Appendix A: Stakeholder and Advocate Interview Question List

- What is your experience supporting people with Dual Diagnosis (DD) within the mental health (MH) sector?
- What would you tell or people with DD trying to access MH services?
- What would you tell service providers trying to support people with (DD) trying to access MH supports?
- What supports or resources are available to help your people using the services at your agency with mental health challenges or crises?
  - Did you get a referral, how else access the services?
  - Who / what stakeholders are important to include in care for people with a DD
- What are the biggest challenges to helping the people using the services at your agency with mental health challenges or crises?
- What is your experience with direct linkages between the DS sector (your agency) and the MH sector?
- What needs to happen in order to help the people using the services at your agency with mental health challenges or crises?
- Would you like to add anything else?

## Appendix B: Person with a DD Interview Question List

A selection of the following questions were asked depending on the person's situation:

- Do you have experience with a mental health diagnosis?
- Can you tell me about you and your mental health / diagnosis?
- Have to ever tried to get support for your mental health /diagnosis?
- What was good about those supports?
- What has been challenging about those supports?
- How do you feel about your psychiatrist (or other support)
  - Likes/ dislikes
- How did you meet your psychiatrist (or other support)
- What other supports or people have been helpful?
- What should happen to make better supports?
- Do you have anything else to add? Did I forget to ask about anything?

## Appendix C: Systems Pathway

### Systems Pathway into mental health (MH) supports:

- **Developmental Services Ontario (DSO):** register with DSO for supports- may have list of services and professionals available to connect with
  - <https://www.dsontario.ca/>
  - <https://www.dsontario.ca/members/register>
  - Connect with a case manager, support worker, day programs
    - Funding for the above: <https://www.dsontario.ca/passport-program>
  - Sunbeam Community Center: <https://sunbeamcommunity.ca/>
    - Sunbeam Developmental Resource Center: <https://www.sdrc.ca/>
      - Ontario Autism Program, Autism Behaviour Consultation, behaviour consultation, counselling, health care consultation, FASD coordination, respite coordination, speech and language consultation, etc.
    - Community Living Services: <https://sunbeamcommunity.ca/community-living-services/>
    - Developmental Services Ontario Central West Region: <https://www.dsocwr.ca/>
  
- **Psychiatry or a diagnosis** is key for MH support
  - Diagnosis gives a clear way forward, and professionals know more about how to support someone if they have a diagnosis
  - **Psychiatrists:**
    - Dr. Kantor, Waterloo Region, Toronto
      - Through Sunbeam Community Services
      - Referral process through Heather Leisegang, Sunbeam Manager of Clinical Supports
        - [h.leisegang@sunbeamcommunity.ca](mailto:h.leisegang@sunbeamcommunity.ca)
    - Dr M. Virey, Mississauga
      - Dr. Maselle G. Virey is currently accepting new patients. To book an appointment, please call (905) 896-1302.
      - <https://www.healthdoc.ca/listing/dr-maselle-g-virey-psychiatrist-mississauga-on>
    - Dr E. Mulder, Guelph

- **Central West Specialized Developmental Services (CWSDS):**
  - “The Dual Diagnosis Service provides comprehensive assessment, treatment planning and interpretation, on-site and follow-up support, mentoring for caregivers, consultation and education.” “CWSDS is proud to provide a wide range of residential and non-residential services that accommodate the most complex needs.”
  - <http://cwsds.ca/en/dual-diagnosis-service/>
  - Information on the CWSDS/[CNSC community referral and screening process](#)
  - CWSDS/[CNSC Community Screening/Referral Form](#)
  
- **Jodi Marleau**, Complex Support Coordinator, Community Networks of Specialized Care—Central West Region
  - Contact for information on CWSDS services that may be appropriate for you
  - 905-808-5309
  - [jmarleau@cwsds.ca](mailto:jmarleau@cwsds.ca)
  - 53 Bond Street  
Oakville, ON  
L6K 1L8
  - fax 905-849-8000
  - [www.community-networks.ca](http://www.community-networks.ca)
  
- **Amber Huffman**, Dual Diagnosis Justice Coordinator (Waterloo, Wellington, Dufferin), Community Networks of Specialized Care
  - Contact for justice system support for people with developmental disabilities
  - 519-504-8211
  - [ahuffman@cwsds.ca](mailto:ahuffman@cwsds.ca)
  - 53 Bond Street  
Oakville, ON  
L6K 1L8
  - fax 905-849-8000
  - [www.community-networks.ca](http://www.community-networks.ca)
  
- **Grand River Hospital Specialized Mental Health/ Dual Diagnosis Clinic:**
  - <https://www.grhosp.on.ca/care/services-departments/mental-health-addiction/specialized-mental-health>
  - Freeport Site  
Specialized Mental Health  
3570 King St. East

Kitchener, ON N2A 2W1

Phone: 519-749-4300 ext. 7472

Fax: 519-894-8308

- [Dual Diagnosis Clinic criteria checklist](#)
- [Dual Diagnosis Clinic outpatient referral form](#)
- Services: mental health emergency care, adult inpatient and outpatient mental health, specialized mental health, family navigator, information for family doctors
- Outpatient services can be accessed through family doctor:  
<https://www.grhosp.on.ca/care/services-departments/mental-health-addiction/family-physicians-referral-forms>
- Mental health emergency care, Adult in and outpatient mental health, specialized mental health, Family navigator, information for family doctors
- **Peel Behaviour Services**
  - outpatient services: counselling sessions, groups, community activities, and psychiatrists will see a person with a DD because they are connected with this program
  - <https://www.peelbehaviouralservices.ca/>
  - Contact and referral information:
    - <https://www.peelbehaviouralservices.ca/contact-us>
- **Here 24/7** – quicker referral to psychiatrists
  - <https://here247.ca/>
- Places for Psychiatry self-referral, don't need a doctor referral
  - **WayPoint** <https://www.waypointcentre.ca/>
  - **St Joe's** <https://stjoestoronto.ca/areas-of-care/outpatient-mental-health/>
- **Family doctor** can be most powerful ally
  - Start with the doctor as portal because a referral from a doctor will/may get someone through door to psychiatrist faster than a waitlist
  - Community Living Cambridge has relationship with Doctors
    - Dr Parker
    - Dr Herrera
  - Dr Iftikhar, Guelph
  - Dr. Rebecca Lubitz, Kitchener
- **Youth transition plans**; there's transition plans from child to adult services, but many families don't follow up on transition plans. Transition plans can be important and

helpful as they help a person with DD get connected with services and have an early entry into adult services

- School board can be a way to get introductions to gatekeepers in services
- **Day program:** <https://liveandlearncentre.ca/>
- **The Ontario Ombudsman:** promotes fairness, accountability and transparency in the public sector by investigating public complaints and systemic issues within his jurisdiction.
  - <https://www.ombudsman.on.ca/home>
  - Advocates wrote about a complaint in policy, had the policy changed. (Used to have to give up custody of child if they were entering a Group Home, this is no longer the case due to a team of families advocating to The Ontario Ombudsman!)
- **Important people and supports to have involved in circle of care:** The person with DD, the person's family, frontline staff, house manager, Psychiatrist, doctor, health therapist, neurologist, dietician, behavioural therapist, 1:1 support, sensory therapy, occupational therapy, Applied Behaviour Analysis (ABA) therapists, court system, community partners, Grand River Hospital, Freeport Hospital, Central West Specialized Developmental Services (CWSDS), police, Brain Injury (BI) specialist, substance-use services.

## What May Help:

- Frontline staff can develop a robust dataset that demonstrates the behaviour / symptoms
  - Need to develop credibility in the face of a professional (mental health support people) that may be skeptical
- Helpful for people and their families to call people at agencies like KWHab, they can at least walk you through process, make friendly introduction to some services
  - People have even reached out to agencies for help at hiring fairs, go there to ask them questions
- Some hospitals may see a person with Dual Diagnosis as already having supports in their group home, so they don't need to be at the hospital. Additionally, it may be thought the crises is due to being a person with a disability rather than experiencing a mental health crisis. Families may try to connect and advocate for their family member with Dual Diagnosis if this is the case, rather than staff from the group home to make the need for services clear.

- Ask if home visits from doctors and support people are available, rather than long or difficult transportation journeys, Zoom appointments are becoming more and more common, this may be a suggestion for an office
  
- Waitlists
  - Connect with the doctors and/or their offices directly
    - An advocate was extremely concerned about safety of her son so wrote email to a doctor directly asking for help. The doctor's office manager responded and got in to see him quickly
    - Doctor called CMHA on behalf of person with a DD and got them connected
  - Reconnect with offices once a month or so to ensure still on the waitlist, unfortunately people can get lost on waitlists. It's okay to call and remind the service their support is still needed
  
- Parent/other support groups
  - People can share supports, what has worked and hasn't worked for them
  - If a structured support group is not a good fit, try to connect with other families/parents in an informal setting for support and to share knowledge
  - Parents/families from day programs may get together
  - Autism Ontario has support groups
    - [https://www.autismontario.com/events?custom\\_326=All&custom\\_325=All&event\\_type\\_id=20&custom\\_356=All](https://www.autismontario.com/events?custom_326=All&custom_325=All&event_type_id=20&custom_356=All)
  - Parent Facebook support group: PAD- Parents of Adult Children with Disabilities Advocacy and Support  
[https://www.facebook.com/groups/161151297720322/?multi\\_permaLinks=1131198350715607%2C1131040230731419%2C1131038534064922%2C1130991640736278%2C1130987587403350&notif\\_id=1620523888702131&notif\\_t=group\\_activity&ref=notif](https://www.facebook.com/groups/161151297720322/?multi_permaLinks=1131198350715607%2C1131040230731419%2C1131038534064922%2C1130991640736278%2C1130987587403350&notif_id=1620523888702131&notif_t=group_activity&ref=notif)