Disability Support Program
Human Rights Remedy Solutions

Literature Review

Multi-Disciplinary and Clinical Supports
Project 4 – Crisis Prevention and Community Response

2024

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Aim and Approach

Aim and Approach

How was the review completed?

Overall, this literature review aims to:

- Explore current evidence related to the *prevention* and *response* of crisis situations for individuals living with disabilities
- Identify and explore best-practice crisis prevention and response strategies for individuals living with disabilities
- Explore opportunities to improve support for individual living with disabilities before and in response to a potential emergency/crisis situation.

In an attempt to capture all potentially relevant literature, we employed a range of search terms into academic and grey literature sources (e.g., google; google scholar; government websites, etc.). This included, but was not limited too:

Concepts: Crisis Prevention & Response.
Terms: crisis response; crisis prevention; emergency response; emergency prevention; urgent response; crisis support plan*; emergency support plan*; crisis support strategy*; crisis management; crisis care; crisis intervention; crisis response plan; de-escalization interventions.

Population: People Living with a Disability(ies).
Terms: disability; complex care needs; chronic condition*; intellectual disability*; developmental disability*; physical disability

Emergency Responses Overview

Overview

Defining a ‘crisis’

An individual with complex needs and challenging behaviours may experience physical, mental, or emotional distress, and behave in ways that cause concern for the safety of themselves and other people.

“Crisis” has been described as a state that occurs when the person’s usual ways of coping with stress are not enough. A crisis begins with the critical incident (crisis) and continues to follow-up and recovery.

For example, an individual may have a critical incident where they are angry and aggressive. If they lose their job as a result, this event becomes another part of the crisis. There are many types of crisis, but some of the most common ones are:

1. **Situational**

A single, unanticipated event occurs in the person’s life; for example, an individual with complex needs have a loved one pass away, or find themselves working in an environment that upsets them (e.g. a noisy, crowded mall)

2. **Chronic**

The person goes in and out of crisis; for example, an individual with complex needs may have mental health problems that improve and then worsen, or housing that is stable and then breaks down.

3. **Transitional**

The person faces changes in demands or their abilities; for example, an individual with complex needs moves from a school to a work setting or is aging and becomes more forgetful and confused.

4. **Environmental**

The person faces changes in their physical environment. This might include power outages, housing problems due to inclement weather, or disruptions to routines due to unsafe weather conditions (e.g, family members unable to visit, etc.

Prevention and Response

Overview

Tools in Crisis Prevention and Management

Crisis intervention involves the methods that are used to assist the individual to cope with the stressful event. Crisis intervention begins with the critical incident and continues to follow-up and recovery.

To Prevent a Crisis

- ✓ Collect as much information as possible before the individual comes into service, by meeting with them, their families, and other people who have worked with them
- ✓ Use the information to develop the individual service agreement – location, hours of support, types of activities, etc.
- ✓ Use the information to develop a behaviour support plan and an individual crisis plan
- ✓ Train staff to the approaches that will be used to support the individual, before they come into service
- ✓ Talk to other professionals (e.g., medical, mental health) in the community and identify what their scope of practice and supports

To Respond to a Critical Incident

- ✓ Set up an on-call rotation, where experienced staff are available to answer an emergency call
- ✓ Select specific staff to form a crisis response team, where their skills and combined presence can help de-escalate
- ✓ Follow the individual's crisis response plan and the service provider's crisis procedures – the staff know what to do and who to call, depending on how the situation develops

To Recover and Plan after the Crisis

- Arrange for a qualified person within or outside the organization to de-brief with the individual and the staff involved
- Have the staff involved and the on-call person write a report describing what happened
- Meet with the team to discuss the incident, and any changes to the type of support the individual requires

Prevention and response | Key elements

Safe spaces of Respite

Persons in distress may seek safe spaces of "respite" from harmful or traumatizing environments, which may have provoked or could sustain the mental health crisis. Respite spaces can provide around-the-clock support for individuals in crisis, through several-day to two-week stays. Such spaces meet key rights principles of empowerment, equality and non-discrimination, social inclusion, and autonomy and dignity, as long as decisions to use them are made by the person in crisis or collaboratively.

Respite services involve peer workers, make pantry and cooking facilities continuously accessible, organize group meetings, and allow residents to come and go and pursue outside activities. Trained lay families or friends can also provide relief outside or inside the home. Both types of respite have been shown to have better outcomes than hospitalization and to safeguard human rights.

The literature recommends that respite services:

1. be responsive,
2. allow for flexibility
3. deliver positive outcomes for the individual

Respite should facilitate social engagement and provide opportunities to develop friendships. Some of the literature was more prescriptive, listing what the elements of respite should be (for example, skill development), and focussing less on a person-centred approach.

Respite if often reported as "a chance to relax" and to have "some down time." Some participants may respite to be a break from their family; this was particularly common in discussions with young adults.

Prevention and response | Key elements

Meaningful Peer involvement

- "Experts by experience," also known as peer workers or peer specialists, are trained to use their personal mental health and psychosocial disability experiences to help persons in crisis. While the personal life experiences of anyone who seeks to help others can be used in powerful ways, interventions based on the unique personal experience of crises and with various treatment responses have been widely embraced.

- When peer workers engage and disclose their personal experiences as it applies to the crisis situation at hand, they support and *empower* the person in crisis in a *non-discriminating* manner that preserves *dignity* and promotes *social inclusion*. Peers should be trained in ways that they can provide support and when to escalate concerns. Peer collaboration has been used by some non-peer respites and collaborative care teams to generate innovative types of support.

- Peer-led services appear to contribute to reducing intervention from law enforcement and the cost of services. In this regard, the extent to which crisis responses require professionalization or can be directly provided by lay or peer practitioners outside medicalized frameworks is an essential question that requires greater attention. To be successful, peer involvement must be meaningful and not be implemented in a tokenistic fashion. In too many instances, peer involvement is encumbered by power imbalances, where peer workers are involved in a superficial manner and have little or no control over crisis responses.

Prevention and response | Key elements

Support Team

The support team for an individual with complex needs includes the personal and professional supports in their lives. Each person has an important role in crisis prevention, which may include:

- Their family members provide information that can help anticipate situations of concern, and support the individual through planning
- The formal guardian advocates for the least intrusive and restrictive approaches that are in the best interests of the individual
- The family doctor monitors the side effects of medication (e.g. drowsiness, agitation, weight gains/loss), and other health conditions (e.g. diabetes, epilepsy)
- The psychiatrist prescribes medication to address diagnosed psychiatric disorders in the individual and reduce behaviours of concern
- The mental health worker teaches the individual coping skills for stressful situations
- The behaviour consultant designs planned approaches for staff to support the individual in stressful situations

The team should meet regularly to ensure that the information provided is clear, consistent and current. By doing so, team members can offer each other suggestions and more immediate assistance. A personal support network is an example of a mixed personal safeguard. The informal part is the volunteer involvement of family and friends and the kinds of things they do with the individual. The formal part is the involvement of paid caregivers and the support from an agency

Prevention and response | Key elements

Safeguards

Partnerships
The new vision of community living requires that we broaden our thinking about who we partner with, and how we do it. Changing the attitudes and economic conditions that affect the lives of people with disabilities is a very big job. Success requires that we find new partners and allies who share some of the same values. Who are the people and organizations in your community who might be interested in working together – even if they are not connected to people with developmental disabilities? How might you change some of the traditional relationships you are involved in?

Examples are:

- Facilitating development of community-based crisis response capacity
- Working with Health Services for Community Living to support people with health care needs
- Working with Mental Health Teams to support people who are communicating using behaviour that is unsafe or concerning to either the person or others.
- Working with service providers to meet contract expectations, including accreditation and program standards
- Establishing Community Councils to provide feedback, strengthen local partnerships, and help develop personal support networks
- Hiring a Self-Advocate Advisor to work with self-advocates and agencies

Prevention and response | Key elements

Safeguards

Informal Safeguards

Relationships between people using supports and those providing supports are very important. Informal safeguards can offer ways to make the relationships between people served and service providers more equal. For example, a strong personal support network that supports an individual or family can help balance the perspectives of the formal system. Personal support networks can also usually respond more quickly than formal services when things go wrong or change.

Supporting Informal Safeguards in the Community:
These are informal safeguards that rely on the interest, caring and goodwill of concerned citizens and organizations. Negotiations of formal safeguards are more likely to involve written agreements with agencies or professionals and may require funding.

Here are some examples:

- A caregiver develops a missing person protocol with the help of the local police.
- A family develops a representation agreement with their adult daughter to help with important decisions.
- A service provider negotiates a protocol with the local hospital about how to best support people with developmental disabilities in the Emergency Department.

Prevention and response | Key elements

Person Centered Planning

Person Centred Planning is a set of approaches that help a person with a developmental disability to explore the things in life that are most important to them. Planning helps people, their family, friends and other members of their support network to focus on key areas of life and identifies:

- **What** to do and how to spend your time. You might work, learn something new, volunteer, pursue hobbies and interests, or a mix of choices;
- **Who** to have relationships with and how to be involved in chosen communities;
- **Where** to live and with whom; and
- **How** to balance health, safety, and risks.

PCP has been identified as having the potential to facilitate improved social inclusion, community participation and quality of life. PCP may provide a good basis to plan community participation and, with the right supports in place, may provide opportunities for people with complex needs to improve their community participation.

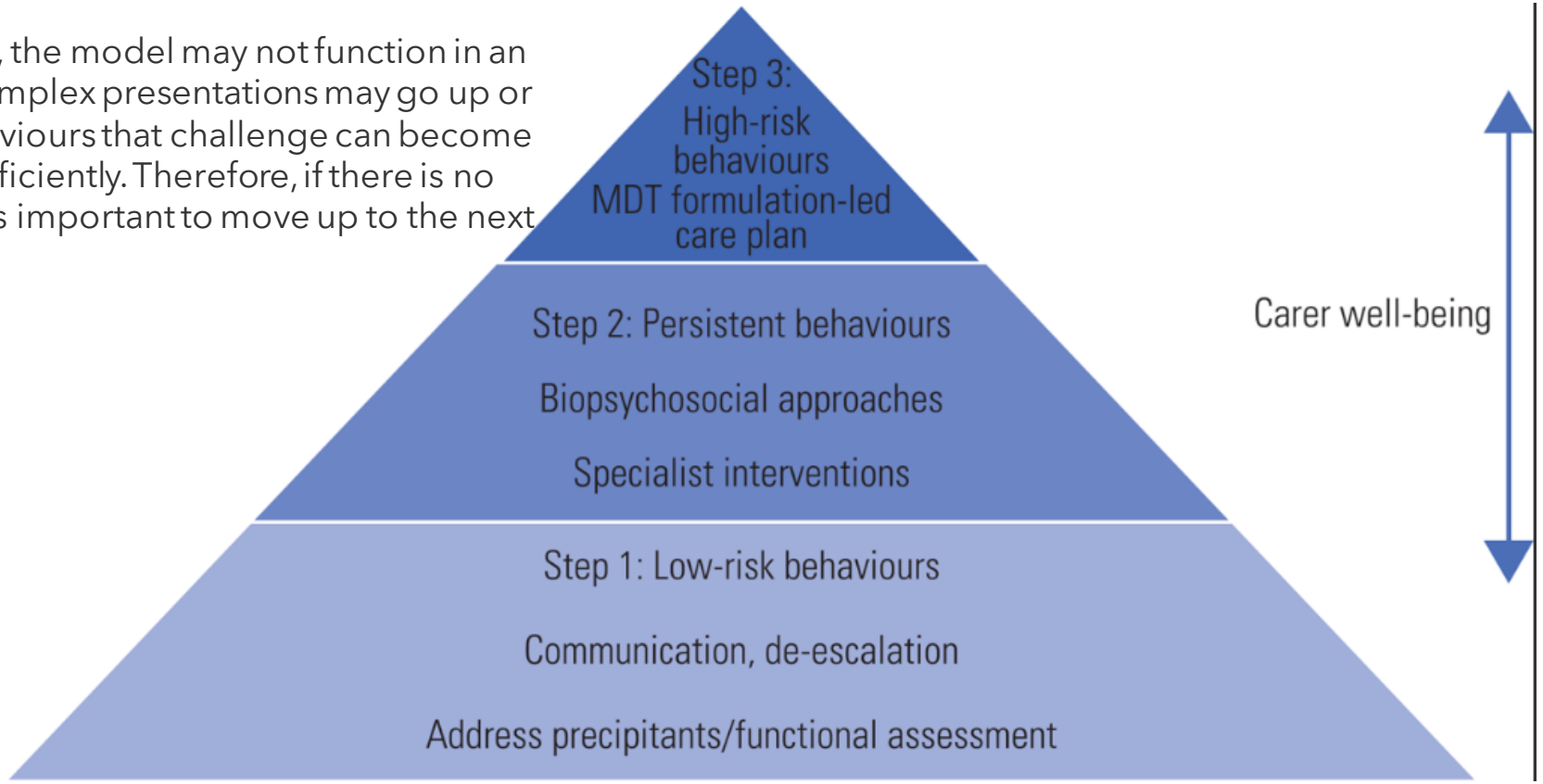
Safeguards need to be implemented and monitored along with the other actions agreed to in a person-centred plan. This can present opportunities to educate others about safeguards and to carry over an understanding of a person's unique vulnerabilities and safeguards into all aspects of their life and support system.

Response Strategy - Examples

Response Strategies \ Examples | stepped care model

The Stepped- Care Model for the assessment and management of challenging behaviour

As indicated by the double headed arrow, the model may not function in an entirely linear way and individuals with complex presentations may go up or down the steps and even skip steps. Behaviours that challenge can become chronic if not addressed effectively and efficiently. Therefore, if there is no response at lower stages in the model, it is important to move up to the next stage.



Response Strategies \ Examples

Step 1: Functional Assessments

Behaviours that pose very low risk of harm to the person or others (including to physical health and general well-being) may require **little or no action** from family carers or direct care staff. Such behaviours could be tolerated while various factors that might precipitate their onset are explored. It is advisable for direct care staff or family carers to raise concerns with the health teams the person is registered with, who will advise on next steps and facilitate, if needed, contact with a general practitioner (GP) for screening or review. After any immediate concerns have been addressed, it is important to use low-intensity interventions such as **functional assessment** to understand the reasons for the behaviour.

Functional assessment of challenging behaviour

- Are used with many populations, including those without intellectual disabilities, to identify the cause of the behaviour and develop hypotheses that are then tested to find a solution.
- Are comprised from the collection of data from direct observations of the individual and from carers, followed by functional analysis. The latter assumes that the behaviour has one of four functions: to gain attention from a social or care network; to escape/avoid a situation, person or activity; to obtain/achieve a preferred object or activity; or to fulfil a sensory need.
- Can be used by non-specialist health professionals who can be trained to carry out these assessments with a view to developing a positive behaviour support (PBS) plan that guides carers to focus on areas of change which are likely to improve communication between family, the person, care staff and professionals.
- This may include development of joint understanding of the person's preferences and personal history, improvements in the physical environment, finding new occupational opportunities and anticipation of times when behaviours that challenge may be more likely to occur, such as when personal care is being given.

Response Strategies \ Examples

Step 1: Functional Assessments Cont.

Functional behavioural assessments outline the individual's daily routine in order to provide continuity when the individual is changing services or enhanced support in their current service. For crisis prevention, the assessment identifies those areas that could provoke anger, frustration or fear responses in the individual:

- **Choices** – what choices can the individual make; how many choices should be presented at one time; how much information does he want or need to make the choice
- **Transitions** – does the individual have difficulty changing activities, such as going from home to work in the morning
- **Routines** – does the individual like to do certain activities at the same time each day; what activities do they not like to do, what changes have been made to accommodate this, what coping strategies been taught'

Response Strategies \ Examples

Step 1: Functional Assessments Cont.

Functional behavioural assessments contain the following:

1) clear operational definition of the problem behaviour(s)
2) identification of the times, places and circumstances in which the problem behaviour(s) occurs and does not occur
3) identification of the factors that precede the occurrence of the problem behaviour (i.e. antecedents)
4) identification of the factors that follow the occurrence of the problem behaviour (i.e. consequences)
5) experimental functional analysis of antecedents and consequences to observe their causal relationship with the target behaviour
6) development of hypotheses regarding the function or relationship between the problem behaviour and the individual's environment, which then lead to proposed intervention strategies
7) ongoing data collection to monitor/revise hypothesized functional relationship and/or implemented intervention strategies

Response Strategies \ Examples

Step 2: Intervention

If initial strategies do not reduce or eliminate the behaviour or risk is increasing, the next step is to turn to manualised interventions that are carried out by trained clinicians.

A number of interventions have been adapted or developed for behaviours that challenge in people with intellectual disabilities. These range from the more common therapies such as mindfulness to intensive interventions to enhance communication in people with more severe cognitive limitations. More recently, there has been interest in the utilisation of eye-movement desensitisation and reprocessing (EMDR) in the treatment of challenging behaviours in adults with intellectual disabilities who have experienced trauma.

These interventions, when available, are usually delivered by professionals from specialist community intellectual disability services or mental health services through locally agreed clinical pathways such as NHS England's Improving Access to Psychological Therapies programme. This step also includes various evidence-based approaches along the biopsychosocial spectrum, such as improving physical health, exercise and activity regimes, social interaction and the use of regular systematic medication reviews to optimise prescription and administration of medication.

Response Strategies \ Examples

Step 3: Multidisciplinary Action

The final step is for the most high-risk situations or individuals who have not responded to steps 1 and 2. These cases are likely to require an in-depth multidisciplinary team formulation for a more detailed understanding of the underlying problems and conceptualisation of the intervention that may be needed within a formulation-led care plan. In the most serious cases it is likely that clinicians may need to consider the option of in-patient admission or of alternatives such as crisis team intervention or respite care.

Management of behaviours that challenge: what should be included in a service pathway

- Set the objectives (who to work with; prevention or treatment only?)
- New referrals and crisis management
- Initial assessment (who will complete it) and risk assessment
- Outcome of initial screening: if referral to the pathway is agreed in multidisciplinary discussion, decide on allocation of care coordinator(s), plan for assessment and interventions, establish the degree of urgency and level of risk
- Those on the pathway will receive profession-specific input (e.g. professionals trained in positive behaviour support, speech and language therapy, occupational therapy, psychiatric review, nursing, social work) and network involvement (e.g. carer education and monitoring plan)
- Use of outcome measures (e.g. Behavior Problems Inventory) and multidisciplinary/multi-agency reviews
- If progress is satisfactory, decide whether to discharge, taking into consideration carer and patient feedback on the experience
- Contact with care coordinator 6 months after discharge

Response Strategies \ Examples | START Model

START Model

The START model is an evidence-based approach to community-based crisis intervention for individuals with IDD. START emphasizes comprehensive support to optimize independence, treatment, and community living. A key step in the model is the development of a Cross-Systems Crisis Prevention and Intervention Plan, which the START clinical team creates with the members of an individual's support team.

This is "an individualized, person-specific written plan of response that provides a clear, concrete, and realistic set of supportive interventions that prevents, deescalates, and protects an individual from experiencing a behavioral health crisis." The plan is strengths-based, proactive, and designed to be used across a variety of settings including a person's home, school, and community. The START clinical team remains engaged with a person's care after the immediate crisis has passed, providing specialized training, clinical expertise, and systems evaluations. The model also includes respite services at designated START Resource Centers.

For example, in New Hampshire, the START Resource Center provides stays up to 5 days for planned respite and up to 30 days for emergency respite. These centers provide a safe, therapeutic environment for crisis prevention. START has been identified as a model program by the US Surgeon General's Report and as a best practice by the National Academy of Sciences Institute of Medicine. The model has now been implemented in 15 states. START has shown to significantly reduce participants' behavioral challenges and improve their mental health. Additionally, START has demonstrated effectiveness in dramatically decreasing utilization of emergency services and inpatient hospital units, in some settings by as much as 40%. The gains made by START are remarkable given the limited evidence for many other crisis intervention programs.

Response Strategies \ Examples | PBS

Positive Behavioural Support (PBS)

PBS is a combination of approaches which mainly aim at altering aspects of the environment that may have an impact on behaviour. These include understanding the triggers that lead to a behavioural outburst, improvement of communication between individuals and their carers, promotion of a person-centred community living and use of specific techniques to achieve changes in behaviour by encouraging pro-social responses from the individual. Therapists were shown how to

(a) fill in behavioural charts;
(b) work on developing interventions for each identified behaviour,
(c) plan interventions using non-contingent reinforcement, skills teaching and differential reinforcement; and
(d) take into consideration the impact of other potential triggers such as ill health.

PBS can be used to:

1.developing a functional assessment of the social and physical context within which challenging behaviour occurs; including direct behavioural observations, interviews, record reviews, and behaviour rating scales.
2.the inclusion and involvement of the family, friends, other family members, care staff and/or therapists;
3.developing, implementing, and evaluating the effectiveness of comprehensive person-centred systems of support aimed at enhancing the quality-of-life of the person using a clear description of the targeted behaviour, triggers or antecedents of the behaviour, maintaining consequences, and the function of the problem behaviour,
4.strategies to reduce the probability of the problem behaviour, including environmental arrangements, personal support, changes in activities, prompts, and changes in expectations
5. Ensuring positive outcomes are maintained via developing friendships and getting involved in the community

Takeaways from hospital transition research

Key takeaways | Transitions

The following program elements are described as best practices in the academic literature:

- **Comprehensive discharge planning.** Prior to discharge, hospital staff organize follow-up services and address patients' financial and psychosocial barriers to receiving needed care, drawing on community resources as needed. Hospital staff call patients one to three days after discharge to address patients' questions, assess symptoms and medications, and reinforce patient/caregiver education.
- **Complete and timely communication of information.** Clinicians in the hospital send discharge summaries to outpatient providers one to two days after discharge, using standardized formats. Essential information includes diagnoses, test and procedure results, pending tests, medication lists, rationale for medication changes, advance directives, caregiver status, contact information for the discharging physician, and recommended follow-up care.
- **Medication reconciliation.** Clinicians reconcile medications at each transition (for example, to inpatient, outpatient, or post-acute care). Clinicians check the accuracy of medication lists and dosages and look for contraindications. Clinicians also assess financial barriers to filling prescriptions and provide medication lists to outpatient providers. Medications can be reconciled by physicians, pharmacists,nurses, or care managers. Patient/caregiver education using the "teach back" method. In this method, patients are asked to restate instructions or concepts in their own words. Education can be supplemented by illustrations and written materials at appropriate reading levels. Education focuses on major diagnoses, medication changes, time of follow-up appointments, self-care, warning signs, and what to do if problems arise. Physicians, nurses, care managers, or discharge planners provide education before and after discharge.
- **Open communication between providers.** Communication occurs between care settings and among multidisciplinary teams within each setting. Responsibilities are clearly defined for the discharging provider and the subsequent provider. The discharging provider confirms that the subsequent provider received the discharge summary and pertinent test results and responds to questions promptly. Information transfer involves physicians, nurses, care managers, office personnel, and information technology staff.
- **Prompt follow-up visit with an outpatient provider after discharge.** Hospital staff schedule follow-up visits prior to discharge. Such visits are generally recommended within seven days of discharge. Providers offer follow-up care, ongoing symptom and medication management, and 24/7 phone access. Physicians, nurses, pharmacists, and/or care managers follow up with patients during office visits, home visits, or by phone.

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Key takeaways | Transitions

- In light of the published research on transitional care and the importance of improving quality of care and addressing preventable readmissions, there are several practical recommendations that should be addressed for all admitted patients
- Patient engagement, including counseling on medication management, red flags, disease-specific management strategies, and resources for addressing post discharge issues.
- Communication with outpatient providers, including rehabilitation and skilled nursing facility staff to ensure appropriate follow-up, medication reconciliation, and management.
- Outreach, through either a follow-up telephone call service or home visit, if applicable, to ensure a safe transition.
- A growing body of evidence indicates that medication reconciliation services promote patient satisfaction and improve treatment outcomes as patients transfer from acute care to post-care settings or home. Clear and comprehensive provider–patient communication is the key to achieving optimal transition of care. This includes the use of post-discharge telephone calls, telehealth services, and home visits.

Summary

Overall Summary

- For individuals with intellectual and developmental disabilities and mental health needs, crisis resources are needed, including after hours. Results clearly identify times and risk factors for mental health crisis contacts, including frequent involvement with emergency responders.
- Peer-led services appear to contribute to reducing intervention from law enforcement and the cost of services. Personal support networks can also usually respond more quickly than formal services when things go wrong or change.
- Respite should facilitate social engagement and provide opportunities to develop friendships.
- PCP has been identified as having the potential to facilitate improved social inclusion, community participation and quality of life. PCP may provide a good basis to plan community participation and, with the right supports in place, may provide opportunities for people with complex needs to improve their community participation.
- **Functional behavioural assessments** outline the individual's daily routine in order to provide continuity when the individual is changing services or enhanced support in their current service. For crisis prevention, the assessment identifies those areas that could provoke anger, frustration or fear responses in the individual
- Applying a tailored care-coordination approach specific to a patient's needs improves the potential for high-quality and efficient care, reducing gaps in care and the potential for unnecessary hospital admissions. Additionally, research from New Jersey supports cost savings related to decreased admissions and length of stay in hospital for adults with IDD who were linked with a coordinated care model. The tool used by Health Links is the coordinated care plan (CCP), which helps patients, and their caregivers identify goals, document health information, and develop a coordinated plan that is tailored to fit each patient's unique needs for health and social support.
- Best practice dictates that any behavioural intervention or support plan for an individual with intellectual disabilities be based upon a systematic and detailed FBA of the problem behaviours. Any individualized intervention aimed at changing problem behaviour that is not preceded by an FBA runs counter to established ethical standards. A planned behavioural intervention should not be driven by intuition but rather by observable and measurable data.

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