Practical Guidance to Support the Preventing the Need for Restriction Guiding Principles

Supporting every individual to enjoy their life to the fullest extent possible and preventing the need for restriction should an area of concern of imminent risk of serious harm emerge.

Preamble: The use of a restriction in the provision of supports and services is a human rights issue and may also be a legal issue. Services have a responsibility to reduce imminent risk of harm, mitigate for a risk of harm and prevent, reduce and eliminate the use of restrictions. With good governance, risk can be reduced, safety maintained and restrictions made redundant.

While guidelines and policies for the use of Restrictions can be helpful in the short term, they run the risk of focusing on the better management of such interventions instead of facilitating the necessary paradigm shift required for a commitment to their prevention, reduction and elimination.

The research indicates the negative impact of restrictions for people as pain/ discomfort, injury, experienced as abuse and/or a form of punishment, human rights infringements, humiliation, traumatisation and negative emotions. There are also similar negative impacts for staff who use restrictions and for others who may witness and/or experience the negative side effects arising from sharing an environment or for the care and love they have for the person being supported.

Excellence in practice is dependent on each HSE and HSE funded agency, relevant government department and our subsequent legislation to evidence a commitment to safeguard individual's Human Rights through the non-use of restrictions when providing care and support where imminent risk of harm is present.

Purpose of this Practical Guidance:

In the course of developing the Guiding Principles for the "Preventing the Need for Restrictions", it was identified that the practices, culture, language etc. around the use of restrictive practices has changed considerably over the past number of years. To this end, the title of the Guiding Principles document was changed from "*The use of restrictive procedures and physical, chemical and environmental restraint*" as the policy/procedure is named in the Health Act 2007 (Care and Support of Residents in Designated Centres for persons (children and adults with disabilities) Regulations 2013 – Schedule 5 – Policies and Procedures to be maintained in the Designated Centre to "*Preventing the Need for Restrictions"*. In order to support staff with the new Preventing the Need for Restrictions Guiding Principles this document has been developed to guide staff in applying the Guiding Principles in practice.

The Practical Guidance is divided into four sections:

1. Applying Guiding Principles to Practical Scenarios (using each of the 8 Guiding Principles for each scenario) – page 3
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Section 1 – Applying Guiding Principles to Practice Scenarios

A: Case study - Paula

Paula is a thirty eight-year-old woman with a genetic disorder, autism and a severe learning disability. She has difficulty identifying pain and to date has been unable to express that she is in pain. She finds change in her routine and environment very difficult to tolerate. She is finding the COVID 19 restrictions particularly difficult due to not being able to swim a couple of times a week. She is also not able to meet her family members as often as she would like. She communicates distress using loud vocalisations which are upsetting for her, but also for her peers and staff. In the past she has suffered with gastric ulceration, low haemoglobin and severe ear infections. It has been recommended that she have a blood test to make sure that her white cells and haemoglobin are normal. She does not tolerate a physical examination easily and many of her examinations for her teeth and ears had to be carried out under anaesthetic.

What is the area of concern of imminent risk of serious harm?

- It is queried if she has an infection or untreated illness?
- Is a blood test the least invasive and most effective diagnostic /assessment procedure?
- Is PRN medication required and if so what is the rationale and does it qualify as a restriction?
- Does she have other behavioural support needs and can her Behaviour Support be reviewed?

1. Human Rights Based Approach

The following reflective questions may be useful:

1. How would Paula like to be supported with her health needs? Remember Paula has the right to be involved in decisions that affect her.
2. How can Paula be empowered to make decisions about her health assessment and options? What are the blood tests seeking to diagnose? Can a stool sample be used; a stomach examination, alternative blood draw methods for example?
3. Has Paula been provided with the appropriate communication supports to understand her health assessment and options? How have other people been included in thinking about this decision with her?
4. Why might a health assessment be difficult for Paula? What can be done to reduce her difficulty? Desensitisation /shaping programme's been implemented and with what effect?
5. Can her Behaviour Support Plan be reviewed? Can her person centred plan be reviewed?

2. Compliance with Legislation and Evidence Based

Individuals who avail of care and support services (for example a section 38/39 service, HSE service provider) are supported to the greatest extent possible in decisions that affect them.

In line with the HSE National Consent Policy and in time the ADM(Capacity) Act, the individual's will and preference and participation in every decision is apparent. Where support is required to assist with a decision, both the type and process of this support is noted.

The services policy on supporting an individual with their decision was used.

3. Capable Environments

The following reflective questions may be useful for Paula together with her keyworker to think about together:

1. How is Paula communicated with? Is information provided in line with her communication support needs?
2. Does Paula have a trusting and positive relationship with her supports (family and staff)?
3. How might Paula like to explore the choices and opportunities in the following areas:
   - Recording her symptoms;
   - Recording pain;
   - Blood draw methods;
   - Screening for stomach ulcers; bloating/stool/burping/reflux/ change in appetite etc.?
   - Symptoms of Infection: screening and observation charts;
   - Access to antacids?
   - A treatment /course of antibiotics?
   - Review her pain medication? Change from NSAIDS to acetaminophen for example?
4. Has she or would she like to seek the views of her family /friends (circle of support)?
5. Has anything changed for Paula recently that might now be impacting on her increase in distress?

4. Governance and Sufficient Oversight

It is important that the plan of support is evidenced based and captures Paula's voice (will and preferences) and agreement with the plan.
Together Paula and her keyworker learned the following: (aka an assessment of the area of concern)

- She was more likely to be distressed post meal-times;
- A stool sample was used, which detected a bacterial infection.

The following plan was developed based on her will and preference:

- A empiric course of antibiotics was prescribed whilst awaiting results
- A plan for de-sensitisation for routine health assessments was developed; which included stomach examination; finger press and squeeze for alternative blood draw methods. Phlebotomist suggests that this can be as and if not more painful than standard phlebotomy
- The outcome was that her Haemoglobin was low which led to requiring urgent full blood tests
- An option for her to access an anti-anxiety /sedative to assist her to participate in a health assessment is made available to her, 'on an equal basis with others' who when all other diagnostic options have been explored require a medication to enable them to participate in a medical examination. This is not a medication used as a restraint.

5. Ongoing Practice Development and Support

- Support Staff reviewed the local services policies on a Rights Based Approach and supporting an individual to participate in decisions related to their care and support.
- The above plan was reviewed by the line manager and support and supervision was provided to support its implementation.

6. Positive Risk Taking

- Some people are nervous and hesitant when participating in health screenings and examinations.
- We have a responsibility to explore and balance, risks, rights and responsibilities. We are duty bearers in the context of a HRBA and Paula is a rights holder.
- To see a 'blood sample' as the only assessment /diagnostic option was deemed the least invasive assessment for the health query.
- The support plan is person centred and supported treatment.
- Services /staff should always evidence practical steps to promote and support people's autonomy, a HRBA and access to treatment and care.

7. Emergency

The following reflective questions may be useful:

1. Is this an emergency? Yes, it was deemed an emergency, based on her symptoms. On receiving her stool sample result there was concern for her well-being
2. Is there an imminent risk of serious harm occurring? Yes, an untreated stomach ulcer can result in serious consequences if not adequately and speedily treated
3. Is there a safeguarding concern? No

8. Language and Terminology

The following reflective questions may be useful:

Is the language used to describe the area of concern" person centred" and "supportive"?

- Paula is described initially by her 'labels'. This speaks of a medical description as opposed to a person centred description.
- Later on in the vignette we learn that Paula loves swimming, misses her family and her pre-COVID 19 routine.
- A need to review her person centred plan and perhaps her Behaviour Support Plan could also be recommended here aligning with a Human Rights Based Approach and a bio-psycho-social environmental model for behavioural support needs.
- It has been recommended that she have a blood test to make sure that her blood parameters are normal. It would be important to establish (by the person who knows her best) her will and preferences. In the past, staff may have used the "best interest" in situations like this.
- Paula has shown us that she does not like to have a physical examination and it would be useful to find out how Paula has been supported to develop her tolerance and coping skills, through de-sensitisation programmes, relationships for example.

B: Case study - Jessica

Jessica is a 48 year old woman who lives in supported living. She likes to shop in charity shops each week spending €20 approx. on a range of items. Over the last few months, she has had difficulty paying her phone bill and last week she did not have enough money to pay her rent. She now owes €120. Staff have suggested that they hold her bank card to help her manage her money.

What is the area of concern of imminent risk of serious harm?

- There are three areas of concern:
    - Breach of her tenancy agreement for not paying rent;
    - Maintaining financial autonomy and independence (with support with income and expenditure).
    - Human Rights Restriction.

1. Human Rights Based Approach

The following reflective questions may be useful:

1. How would Jessica like to be supported with her bills, income and budgeting? Remember Jessica has the right to be involved in decisions that affect her.
2. How can Jessica be empowered/enabled to make decisions about her income and expenditure?
3. Has Jessica been provided with the appropriate communication supports to understand what may happen if she does not pay her bills?
4. Why might budgeting and bill paying be difficult for Jessica at this time?
5. Is Jessica vulnerable to financial exploitation and abuse?

2. Compliance with Legislation and Evidence Based

Individuals who avail of care and support services (for example a section 38/39 service, HSE service provider) are supported to the greatest extent possible to manage their private property and finances in line with best practice and National legislation Standards and Guidance for Designated Centres – Residents' Finances as set out by HIQA.

There should be comprehensive procedures in place to safeguard an individual's finances and private property when support is provided by a service. It is acknowledged that the management of finance and private property on behalf of individuals can leave staff/services open to allegations of abuse or misuse of finances, as such full transparency is required.

In line with the HSE National Consent Policy and in time the ADM(Capacity) Act, the individual's will and preference and participation in every decision should be apparent. Where support is required to assist with a decision, both the type and process of this support is noted.

The service's policy on managing and supporting an individual with their finances was reviewed.

3. Capable Environments

The following reflective questions may be useful for Jessica together with her keyworker to think about together:

1. How is Jessica communicated with? Has Jessica been provided with the appropriate communication supports to make decisions about her income & expenditure??
2. Does Jessica have a trusting and positive relationship with her supports (and staff)? What is Jessica's weekly income and expenditure?
3. How might Jessica like to explore the choices and opportunities in the following areas: (perhaps as part of her person centred plan)
    - Does Jessica have an opportunity to increase her weekly income?
    - Is Jessica entitled to any income support?
    - Does Jessica have a savings plan, in line with her wishes?
    - Does Jessica's person centred plan consider and support income and expenditure goals?

4. What support would Jessica like with budgeting?

5. Has she or would she like to speak to her family /friends (circle of support) about budgeting, income and expenditure?

6. Has anything changed for Jessica recently that might now be impacting on her increase in spending?

4. Governance and Sufficient Oversight

It is important that the plan of support is evidenced based and captures Jessica's voice and agreement with the plan.

Together Jessica and her keyworker learned the following: (aka an assessment of the area of concern)

- She was using more data on her mobile phone(with Whats App) and this increased her monthly bill from €30 a month to €70 a month;
- Her supported living environment did not have WiFi;
- She was buying more takeaway coffees and ready-made meals, costing an extra €30 a week on top of her €40 weekly grocery shopping.
- Her sister's wedding was coming up and she was paying off on a mirror that she had bought for her as a wedding present.
- Jessica said that she was just tapping her card now and never knew how much money she had in her account.

Jessica and her keyworker agreed the following plan:

- Request WiFi in her supported living environment;
- Review her phone contract and data bundle;
- Support with cooking lunch/ dinner;
- Reduce takeaway dinners to once a week.
- Agreed to pay €20 a week towards the rent owed.
- Savings of €10 a week agreed once the mirror was paid off;
- Ongoing support and conversation occurred at Jessica's weekly keyworker meetings where she could review her needs;
- Review her current job and hours to see if there is an opportunity to increase her income;
- Review her entitlements.
- This plan was documented in video discussion with Jessica.

The plan resulted in Jessica getting free WiFi in her home; her phone contract was reviewed and a €30 a month contract was sourced with increase data bundle; she joined a weekly cooking class which she enjoyed; and she is looking for a second job at the moment. She is also trying out a new Budget App with her keyworker.

5. Ongoing Practice Development and Support

- Support Staff reviewed the local services policies on a Rights Based Approach and managing and supporting individual's finances;
- The above plan was reviewed by the line manager and support and supervision was provided to support its implementation.

6. Positive Risk Taking

- Over-expenditure can and does occur for many people.
- We have a responsibility to explore and balance, risks, rights and responsibilities. We are duty bearers in the context of a HRBA and Jessica is a rights holder.
- To hold Jessica's bank card would have restricted her human rights (specifically Article 12 Equal Recognition Before the Law)
- The support plan is dynamic and responsive. It is person centred and does not restrict any of Jessica's rights.
- Services /staff should always evidence practical steps to promote and support people's autonomy.

7. Emergency

The following reflective questions may be useful:

1. Is this an emergency? No
2. Is there an imminent risk of serious harm occurring? No
3. Is there a safeguarding concern? No

8. Language and Terminology

The following reflective questions may be useful:

Is the language used to describe the area of concern person centred and supportive:

- Staff have suggested that they hold her bank card to help her manage her money.
- The word 'hold her bank card' conveys that staff will control Jessica's expenditure.
- The statement to 'help her manage' conveys that Jessica is 'not able' to do this. This contradicts a support model of disability and a Human Rights Based Approach.

C: Case study - Jimmy

Jimmy is a 37 year old man who lives in a group home. He has moderate learning disability and autistic spectrum disorder. Jimmy has always been a placid calm man but can get very excited and agitated when his routine is changed. Recently due to COVID 19 restrictions he has no longer been able to go to his day service regularly and his visits home to his parents have been curtailed due to public health guidelines and risk of infection. Since this has happened, he has become very distressed, is not sleeping at night and keeps other residents awake in the house due to his loud screams. He has also started high pitched screaming at times during the day for no particular reason. Due to the complaints from the other residents, his staff have asked for the GP to treat his agitation and have asked for sleeping tablets and PRN medication to stop him screaming.

What is the area of concern of imminent risk of serious harm?

- It appears that Jimmy is experiencing extreme emotional, psychological and physical distress and exhaustion;
- Safeguarding concern for other peers;
- Use of medication as a restriction,
- Stressful working environment for staff.

1. Human Rights Based Approach

Jimmy has a right to bodily integrity.

His behaviour may be serving as a communication of distress i.e. he may be missing his routine and his family. There may be new staff in his unit or he may be in discomfort or pain.

The first step would be to evaluate the causation of his behaviour and to look at what purpose(s) his behaviour is serving.

Medication cannot be used as a treatment for agitation without a thorough explanation of the underlying causes. The only person that can consent for any recommended assessment and/or treatment is Jimmy.

2. Compliance with Legislation and Evidence Based

HSE Guiding Principles on behavioural support were consulted;

HSE Safeguarding Policy

Sleeping tablets cannot be prescribed as a substitute for inadequate resources, assessment, supports and/or staffing.

There must be a medical or psychiatric indication for medication.

3. Capable Environments

The multidisciplinary team in Jimmy's service assessed Jimmy and asked if the General Practitioner could see him also to rule out any underlying issues, whilst they were looking for other causes.

It was felt by the multidisciplinary team that Jimmy was trying to communicate how he felt through his behaviour.

Further exploration identified that there had been numerous changes to staff due to the COVID 19 crises.

At night these staff were sleeping, there was no one awake at night to be able reassure and to redirect Jimmy back to bed.

4. Governance and Sufficient Oversight

The multidisciplinary team, together with Jimmy and his staff team developed a comprehensive plan which included a request for increased funding for the service, specifically for an additional 1 WTE day support staff.

A case worker took over the governance of this plan and insured that all the actions from this plan were put in place with a particular focus on 'meaningful day' and a variety of ways to maintain contact with his family, including physical distanced visits. Safeguarding reports and plans were developed for the peers in the house.

5. Ongoing Practice Development and Support

The staff team together with Jimmy also developed a plan to support Jimmy's sleep routine. The plan included use of a calming bedtime routine, the decrease of blue light, ensuring the room was of an adequate temperature and well ventilated and a variety of caffeine free hot drinks were available.

The staff felt that this work enhanced their own understanding of sleep and also helped them with other people in the house who were having difficulty with their sleep routine.

6. Positive Risk Taking

On looking at Jimmy's circumstances, and the fact that he had not any visits from his family, Jimmy together with his family agreed a protocol for garden visits.

This was discussed by the social care team in the house in collaboration with the multidisciplinary team.

It was agreed that contact with his family was of critical importance and could occur in the context of the current public health measures. Family contact was reassuring for both Jimmy and his family, as they were concerned that he was so upset.

7. Emergency

This situation was considered to be emergency. Safeguarding plans were required and an assessment and support plan for Jimmy's behavioural support needs was also implemented.

8. Language and Terminology

- Sleeping tablets are a medication that should only be used in consultation with a GP or a medical Doctor.
- They are only licensed for six weeks and are potentially addictive if used for longer periods than this.
- They work by helping a person to enter a sleep cycle but do not work on maintaining the sleep architecture.
- If used improperly they can lead to addiction and can also lead to increased falls in vulnerable people.
- They are never a solution to inadequate staffing or an inappropriate environment.
- A short term PRN medication for agitation may be used in a state of high arousal when there is a risk of imminent harm to a person or other people, but should not be used as a substitution for a thorough evaluation and an analysis of behaviours or concerns.
- Medication may only be used for the treatment of an underlying physical or mental health condition and may not be used to treat behaviours of concern as they may mask the underlying causation and may lead to inadequate diagnosis and subsequent inadequate and unethical management of this.

D: Case Study: Sam

Sam is an 18-year-old autistic man who has a severe intellectual disability. Sam recently moved into his own home, a single occupancy service, after a crisis at home where his support needs could not be met. Sam is supported by two staff. Sam is physically fit and active. He enjoys jumping, running and loves to spin with his arms out while laughing. When he becomes distressed Sam shouts loudly, rips his clothes, throws his body against hard surfaces, punches his head with force, throws objects and hits out or pushes anyone else in his space. Sam's team are committed to maintaining his safety and their safety at times when Sam is acutely distressed. They ask him to go to the hall where Sam has access to his bedroom and bathroom and they lock the door until Sam has calmed down. Sam is unsupervised at these times and staff are concerned that he may hurt himself.

What is the area of concern of imminent risk of serious harm?

- Physical and mental health: It is queried if he has an infection or untreated illness? Is there a mental health issue?
- Physical self-harm: Is there a risk of self-harm? Is Sam a risk to himself when unsupervised while in distress?
- Safeguarding: Is the locked door traumatic for him? How did he consent to this intervention?
- Who has Clinical governance and authorisation of the locked door, which is a restrictive practice?
- Staff safety and wellbeing at work: Is there a risk to staff? What training and support have staff received?
- Is PRN medication required and if so what is the rationale and does it qualify as a restriction?
- Behavioural support plan: Can his Behaviour Support Plan be reviewed?

1. Human Rights Based Approach

The following reflective questions may be useful:

1. Right to behavioural assessment and behavioural support for his distress.
   How would Sam like to be supported when in distress? Remember Sam has the right to be involved in decisions that affect him. People who know him well should inform the assessment and intervention also.

2. Right to independent advocate. How can Sam's will and preference be supported as part of the assessment and development of a support plan? How can Sam be supported to understand the new living arrangements and contact with his family? How are the staff discovering his preferred interests and activities? How do the staff know when he is happy or upset? Has Sam been provided with the appropriate communication supports?

3. Does he have a transition plan that could help inform staff as to his preferred lifestyle. Does he have a Behaviour Support Plan that can be reviewed? Does he have a person centred plan that can be reviewed?

2. Compliance with Legislation and Evidence Based

Individuals who avail of care and support services (for example a section 38/39 service, HSE service provider) are supported to the greatest extent possible in decisions that affect them.

In line with the HSE National Consent Policy and in time the ADM(Capacity) Act, the individual's will and preference and participation in every decision is apparent. Where support is required to assist with a decision, both the type and process of this support is noted.

The services policies in behaviour support, restriction free environments, transition planning for young adults with autism- moving from family home to supported living/residential support; safeguarding vulnerable adults; and consent and decision making were considered.

3. Capable Environments

The following reflective questions may be useful for Sam together with his staff to think about together:

1. How is Sam communicated with? Is Information given in an accessible way? Do staff understand his communication style and how to engage meaningfully with him? Does he have a communication passport and/or behaviour support plan?
2. Are staff knowledgeable about autism ie Autism Awareness training and how this impacts on Sam's needs?
3. Does Sam have access to trusting and positive relationship from his family network while he builds relationships with staff?
4. What is in place to provide security and consistency throughout his day and how is this communicated to him?
5. Are staff sensitive to early signs of distress and have they interventions that can decrease the frequency of self-harm?
6. Have staff sought what works and doesn't when Sam is distressed?
7. Have the team explored strategies to help Sam regulate his distress?
8. Does Sam have a GP and MDT advice to support alternative positive approaches to his distress?
9. Is the physical environment suitable to keep Sam and staff safe?

4. Governance and Sufficient Oversight

It is important that the plan of support is evidenced based and captures Sam's voice (will and preferences) and matches his needs (agreement with the plan.)
Together Sam and staff learned the following: (aka an assessment of the area of concern)

- He was more likely to be distressed post family phone calls or visits; need preferred activity planned post family contact.
- A medical exam noted that he had an ear infection.
- A mental health assessment noted he was experiencing signs of anxiety and depression due to the significant life event of moving away from home;
- Changes to planned routines increased his distress;
- Large personal space needs;
- Staff chatting to each other cause distress;
- Sudden noises like phones, doorbells or passing sirens;
- A low arousal environment works well;
- Physical exercise helps with stress and anxiety;
- MDT support helpful- specifically sensory schedule; and relaxation techniques;
- Layers of clothing and strong comfortable material can maintain dignity and replace the sensory need with a positive alternative;
- Sam's behaviour support plan was updated and a checklist to monitor implementation was developed and scored each week.
- Is information provided in line with his communication support needs?
- Is there evidence of a commitment to using appropriate communication supports including the use of technology?

5. Ongoing Practice Development and Support

- Support Staff reviewed the local services policies on a Rights Based Approach and supporting an individual to participate in decisions related to their care and support.
- The above plan was reviewed by the line manager and support and supervision was provided to support its implementation.
- Behavioural Support Practitioner together with the MAPA trainer also advised re alternatives in response to distress (based on the reason/unmet need of distress)
- Staff supervision and support provided using the ALERT –ME model and also availability of EAP

6. Positive Risk Taking

- We have a responsibility to explore and balance, risks, rights and responsibilities. We are duty bearers in the context of a HRBA and Sam is a rights holder.
- To lock a door may not the least restrictive response to distress.
- Asking him to go to the hall is not giving him a strategy to regulate his distress.
- The support plan is person centred and supported positive alternatives.
- Services /staff should always evidence practical steps to promote and support people's autonomy, choice and a HRBA to access intervention and care.

7. Emergency

The following reflective questions may be useful:

1. Is this an emergency? Yes, it was deemed an emergency, based on his intensity of self-harm and being unsupervised while distressed.
2. Is there an imminent risk of serious harm occurring? Yes
3. Is there a safeguarding concern? No

8. Language and Terminology

The following reflective questions may be useful:

Is the language used to describe the area of concern person centred and supportive: Sam is described initially by his 'labels'. This speaks of diagnostic professional labels as opposed to a person centred description. In the vignette we learn about Sam's behavioural expressions of distress and no mention of his emotional expression of distress especially in light of the significant move from home to an unfamiliar setting without any preparation. It highlights the importance of transition planning which PDS suggests from 2nd year in secondary school. A need to start a person centred plan and a Behaviour Support Plan here aligning with Human Rights Based Approach and a bio-psycho-social environmental model for behavioural support needs. It is not apparent from the vignette that Sam's will and preference for daily routines and preferred activities was considered. The use of a locked hallway unsupervised possibly suggests huge fear of Sam although staff report that they are concerned that he may self-harm and are not comfortable with this approach. It highlights the need for MDT approach for example to develop tolerance and coping skills through autism specific preferred timetabling and communication supports, and through autism specific emotional regulation interventions.

E: Case Study - Tom

Tom is a 37-year-old autistic man who lives in a group home with three other men. Tom drinks high volumes of fluids (e.g., water, milk, yoghurt). Staff recorded that Tom can drink on average of 11-12 litres of fluid per day and on one occasion up to 23 litres resulting in hospitalisation. When Tom is redirected from the kitchen tap, Tom may go to the bathroom and use a vessel to drink from the toilet or he may say 'no water'. The staff team have been advised that it is medically unsafe for Tom to drink more than 3 litres of water each day. Staff are unsure how they are going to manage this advice.

What is the area of concern of imminent risk of serious harm?

- There are three areas of concern:
    - Is there an undiagnosed physical illness?
    - Is there an undiagnosed mental health need?
    - Is there an imminent risk of Tom causing physical injury to himself?
    - Staff require support as they are aware that there are a number of human rights restrictions which may need to be considered. What might be the impact of these for Tom and for his peers sharing the house?

1. Human Rights Based Approach

The following reflective questions may be useful:

1. How would Tom like to be supported with his behavioural support need?
2. What assessment and treatment options have been made available to Tom?
3. Has Tom been provided with appropriate communication supports to understand what may happen if he drinks more than 3 litres a day?
4. How does Tom perceive 'redirection' away from a tap for example; or supervision when using the bathroom?
5. Is Tom living in a home that is suitable for his needs?
6. Does Tom have a meaningful day, with friendships, fun and value?

2. Compliance with Legislation and Evidence Based

Individuals who avail of care and support services (for example a section 38/39 service, HSE service provider) are supported to the greatest extent possible in decisions that affect them.

In line with the HSE National Consent Policy and in time the ADM(Capacity) Act, the individual's will and preference and participation in every decision is apparent. Where support is required to assist with a decision, both the type and process of this support is noted.

The services policies in behaviour support, restriction free environments, transition planning; safeguarding vulnerable adults; and consent and decision making were considered.

3. Capable Environments

The following reflective questions may be useful for Tom together with his staff to think about together:

1. Has Tom had access to a complete medical review; which includes mental health and physical health?
2. Is there an evidence based assessment and understanding of Tom's behavioural support need of 'drinking excessive amounts of liquids'?
3. Does Tom have a meaningful day? If he wasn't seeking a drink what would he be doing or asking for?
4. How is Tom communicated with? Is Information provided in line with his communication support needs? Do staff understand his communication style and how to engage meaningfully with him? Does he have a communication passport and/or behaviour support plan? How does Tom ask/initiate activities/events etc.?
5. Are staff knowledgeable about autism i.e. Autism Awareness training and how this impacts on Tom's needs?
6. Does Tom have access to trusting and positive relationships from his family/friend network while he builds relationships with staff?
7. What is in place to provide security and consistency throughout his day and how is this communicated to him?
8. Are staff sensitive to early signs of distress and have they interventions that can decrease Tom's 'drink seeking behaviour'?

4. Governance and Sufficient Oversight

It is important that the plan of support is evidenced based and captures Tom's voice (will and preferences) and matches his needs and agreement with the plan. Together, Tom and staff learned the following: (aka an assessment of the area of concern)

- Following a medical review it was identified that Tom met the criteria for a diagnosis of secondary polydipsia, with a rare form of diabetes identified. However with treatment, polydipsia continued and this was diagnosed as primary polydipsia. It was also identified that Tom had previously been prescribed an anti-psychotic medication that had the side effects of dry mouth and stimulating thirst. This medication was subsequently reduced and eventually withdrawn.
- A behaviour support plan was developed for Tom based on the medical diagnosis of primary polydipsia. This plan included proactive strategies, skills teaching, focused supports and redirection strategies with three very specific environmental controls;
    - Taps in bathroom with a slow flow mechanism;
    - Shower – water stop cock mechanism
    - Locked fridge at night-time, however this was not implemented. Tom's peers did not agree and made a complaint. Instead a awake-night staff was approved.
    - Cone shaped paper cups were available to Tom.
- The short-term and long-terms risk of polydipsia for Tom were identified; and this information was shared with Tom, his staff team and his family in an accessible format.
- Pain checklist and pain treatment was agreed; specifically, for reflux, however migraine was also queried.
- He was more likely to be seek a drink when he had no other activity available to him; so a meaningful day was created, which included work outdoors which he really enjoyed, activity sampling was also put in place.
- He loved being outdoors; so rain gear and a garden gazebo were actioned. Hillwalking became part of his weekly schedule.
- Human Rights and Equality Committee reviewed the support plan to ensure due process for the rights restrictions;
- Two disciplines (with at least one with expertise in behavioural support and both actively involved in providing Tom's care and support) authorised the environmental restrictions and sought consent from Tom in line with the HSE National Consent Policy.
- Tom's behaviour support plan was updated and a checklist to monitor implementation was developed and scored each week.
- Staff documented each occasion the environmental restriction was relied upon to reduce fluid intake.

5. Ongoing Practice Development and Support

- Support Staff reviewed the local services policies on a Rights Based Approach and supporting an individual to participate in decisions related to their care and support.
- The above plan was reviewed by the line manager.
- Psychologist (providing Behavioural Support) together with the OT provided ongoing support to Tom and his circle of support.

6. Positive Risk Taking

- We have a responsibility to explore and balance, risks, rights and responsibilities. We are duty bearers in the context of a HRBA and Tom is a rights holder.
- As a rights holders, Tom also has the right to take risks. Tom understood that his tummy and his brain did not like 'lots of water' and he would say 'one more drink'.
- It was also agreed that supervising Tom at all times would be a more restrictive intervention.
- As such, the 3 environmental controls were identified as the least invasive yet rights restrictive interventions, thus requiring strict governance and monitoring including due process through the Human Rights and Equality Committee.

7. Emergency

The following reflective questions may be useful:

1. Is this an emergency? No, In the short-term each incident can be managed with supervision. However supervision is not preferred by Tom.
2. Is there an imminent risk of serious harm occurring? No
3. Is there a safeguarding concern? No

8. Language and Terminology

The following reflective question may be useful:

Is the language used to describe the area of concern person centred and supportive?

Tom is described in the context of a specific behavioural support need and possible undiagnosed medical condition called polydipsia. There is no sense of who Tom is other than an autistic man who lives with three other men in a group home.
The description does capture a serious health concern and also recognises a staff team in need of advice on how to manage this behaviour support need.
This is a complex need and warrants interdisciplinary support and assessment.

Section 2: Sample Prompt questions:

1. Human Rights Based Approach

The following reflective questions may be useful:

1. How would the individual like to be supported? Every individual has right to be involved in decisions that affect them.

2. How can the individual be empowered to make this decision?

3. Has the individual been supported with accessible information about this decision?

4. Why might this decision be important for the individual?

5. Is the individual vulnerable to exploitation and abuse in the context of this decision?

6. What right(s) does this decision relate to?

7. How can the decision making process be recorded /noted?

2. Compliance with Legislation and Evidence Based

Name and evidence the policy/legislation and/or regulation that were used to inform and guide the care and support for the area of concern of imminent risk of serious harm.

3. Capable Environments

The following reflective questions may be useful for the individual together with her keyworker to think about together:

1. How is the individual communicated with? Is Information given in an accessible way?

2. Does the individual have a trusting and positive relationship with /his her supports (and staff)?

3. How might the individual like to explore the choices and opportunities available perhaps as part of his/her Personal Plan (and person centred plan)

4. What support would the individual like in the context of supporting the area off concern of imminent risk of serious harm?

5. Has she/he or would she/he like to speak with her/his family /friends (circle of support) about the area of concern of imminent risk of serious harm?

6. Has anything changed for the individual recently that might now be impacting on this area of concern of of imminent risk of serious harm?

4. Governance and Sufficient Oversight

It is important that the plan of support is evidenced based and captures the individual's voice and agreement with the plan. There is evidence of:

- Identification and Assessment of the area of concern is evidenced and completed by suitably qualified professionals.
- The development of the Plan, to include the process of decision making and Consent:
- There is evidence that the individual participated in the assessment;
- The implementation of the plan is supported and evidenced and the correct notification has occurred.
- There is evidence of a commitment for the non-use of a restrictive practice;
- The plan for an area of concern of imminent risk of harm (with or without the use of a restriction) must be reviewed by the healthcare professionals who (and/or the interdisciplinary team) who authorised the plan of care and support and if applicable the use of a restriction at a minimum once every 6 months or more frequently as required.

5. Ongoing Practice Development and Support

How have support staff (and family if appropriate) been supported to review local policies; to participate in this decision making process; to implement the support plan and to participate in an evaluation of the support plan.

6. Positive Risk Taking

- Is there evidence that the individual together with the circle of support have explored all opportunities to balance, risks, rights and responsibilities? We are duty bearers in the context of a HRBA and every individual is a rights holder.
- Is there evidence that the Services /staff took all practical steps to promote and support the individual's autonomy in decision making as it relates to the area of concern of imminent risk of harm.

7. Emergency

The following reflective questions may be useful:

1. Is this an emergency?
2. Is there an imminent risk of serious harm occurring?
3. Is there a safeguarding concern?

8. Language and Terminology

The following reflective questions may be useful:

Is the language used to describe the area of concern of imminent risk of serious harm person centred, constructive, compassionate and supportive?
Is there evidence of a commitment to using accessible communication methods including the use of technology?

Section 3: Case Studies:

This section provides case studies which can be used for workshops to raise awareness about how the guidelines 'Preventing the Need for Restrictions' can be applied and practiced.

1. Use of medicine as restraint or treatment:

These are a few examples of when medication is used both correctly and incorrectly. The cases are mixed to show why a medication could be viewed as a restraint in one situation is not in another.

- Mary is a 30 year old woman with a history of severe learning disabilities secondary to a genetic disorder. Her genetic disorder is complex and involves her not being able to express when she is feeling pain. She also has a diagnosis of autism which means she finds it hard to tolerate any change in her environment. She is particularly finding the COVID restrictions difficult as she is not able to attend the day service as often as possible. She is not able to meet her family members as often as she would like and other residents in the house are finding her behaviour very difficult to cope with. In the past she has suffered with gastric ulceration, low haemoglobin and severe ear infections, it has been recommended that she have a blood test to make sure that her white cells and haemoglobin are normal. She does not tolerate a physical examination easily and many of her examinations for her teeth and ears had to be carried out under anaesthetic.

- John requires urgent dental treatment for an abscess. He has been very fearful of attending the dentist in the past. A single, low dose, short acting anxiolytic is prescribed to treat his anxiety in this situation and thereby support his access to healthcare.

- Anne is due to have routine blood tests in 4 months. In the past she has always become very distressed with this procedure. No action or reviews of her difficulties with this procedure are noted and a single, low dose of anxiolytic is given just prior to her appointment.

- Robert is due to have routine chiropody in 4 months. In the past he has always become very distressed with this procedure. His team start a programme of desensitisation using foot message, foot spas and social stories. Although Robert is much more comfortable having his feet touched he is still unable to let anybody cut his nails. Following a discussion with Robert a single, low dose of anxiolytic is given just prior to his appointment. He is happy to continue his programme of desensitisation knowing he will have further appointments in the future.

- Julie likes pottering around her community house until midnight. Sleep-over staff want her to go to bed earlier and sleep as the staff may be woken during the night to support others in their care. Julie is administered a PRN hypnotic at 22.00 to facilitate an early night.

- Sarah is non-verbal, has ASD and difficulty communicating her needs. On Monday she appears very distressed and starts banging her head off the edge of a wall. Staff administer PRN Paracetamol for suspected pain with a reduction in this behaviour in one hour. On Tuesday Sarah appears distressed again and starts banging her head off the edge of the wall. Staff administer a PRN anxiolytic for suspected distress of unknown cause. Sarah is more relaxed and ceases head banging in an hour. On Wednesday Sarah appears distressed again and starts banging her head off the edge of the wall. Staff administer a PRN antispasmodic for suspected stomach cramps. Sarah is more relaxed and ceases head banging in an hour.

- Peter is an elderly man living in a staffed community house. He takes 2 antidepressants, a benzodiazepine, mood stabiliser and antipsychotic every day. His current staff do not know why these were prescribed and although the GP renews the prescription every 6 months, Peter has not had a psychiatry review in 6 years nor a change to his psychotropic medication.

- Joan is an elderly woman living in a staffed community house. She takes 2 antidepressants, a benzodiazepine, mood stabiliser and antipsychotic every day. She has been attending her GP and psychiatrist regularly and a plan for de-prescribing has commenced with mixed results. There is evidence as to the rationale for the plan and the outcome of previous adjustments of her psychotropic medication.

2. Consideration of human rights

- Brian uses lamh to communicate. Some staff have attended a one day introduction training on lamh signs whenever they can be released as it is not on the mandatory training list. Most of the time Brian is supported by staff who are not using his preferred communication system.

- David lives on a residential campus. He is young, energetic and loves to run unexpectedly while out walking. Staff are unable to run as fast as David and are concerned about his safety in the community. Staff request a wheelchair for David while in the community as this would be safer and enable him to get out more.

- Ann lives in a group home. Sadly her dad died and her mum requested that Ann not be told. Mum wanted to tell Ann in her own time. Mum reported she couldn't cope with her own grief and Ann's at the same time. Mum eventually told Ann 5 months after Dad died.

- John lives on a residential campus. Sadly his Mum died. His Mum had told the family that John could be told when she died but that she didn't want John at the funeral. The family followed Mum's wishes and John didn't attend the funeral.

- Maria lives in a supported living home. She was left money in her father's will. Her brother as executer manages this account. Mary reports that she doesn't know how much is in this account. Maria reports that she is happy that her brother is minding her money from dad.

- Tom lives in a group home with 3 ladies. He doesn't like to go window shopping like the ladies. He requested to stay home while the ladies went shopping. There is one staff working in the house with a float staff at times. Tom then asked if he could stay alone in the house. When Tom went home to his Mum he often stayed home alone while she went to the hairdressers. Staff felt this was too risky to try in the group home.

- Louise lives with her mum. They live on Mum's carers allowance and Louise's disability allowance. Louise attends day services and respite. Louise told staff she would like to move out of home. Mum doesn't want Louise to leave home.

- Mark lives with his elderly parents. Mark is thirty years olds and loves socialising with friends. During the winter months his parents don't like Mark going out in the dark. They also don't like driving in the dark so Mark can't get to his activities and spends most evenings alone in his room. His parents have a plan to keep caring for him as long as they can and then report that his siblings will take over. They will not discuss other options.

- Paul lives at home with his parents. He attends day services. He likes to go out on outings and when out if he sees something he likes would like to buy it. His mum has put a 50euros a day limit on his bank card. This can cause distress to Paul when an item he wants is over the 50euros limit. Mum insists that he will spend all his money if there are no controls.

- Mary went to a mainstream school and enjoyed it. Her teachers and parents decided that she would be better supported in a special school now that she was going into secondary school.

- Jack's parents want him to go to the same school as his siblings. The principal of the school says they cannot accommodate a child with special needs and that special schools are the best choice for Jack.

- Paul and his brother Alex both have mental health issues. Alex his brother doesn't have an ID so receives his mental health supports from the local community mental health team. He receives the full range of services from inpatient to in home supports to rehabilitation team. Paul has a severe ID and his Mum expected that he would get the same mental health supports from the local community mental health team. However Paul was excluded from accessing the community mental health team.

- Jessica is a 48 year old woman who lives in supported living. She likes to shop in charity shops each week spending €20 approx. on a range of items. Over the last few months, she has had difficulty paying her phone bill and last week she did not have enough money to pay her rent. She now owes €120. Staff have suggested that they hold her bank card to help her manage her money.

- Michael, who is 31 years old lives in a group home. He has a long-term girlfriend who is not allowed stay overnight in his home. He continues to request permission, but is told no and reminded that this is what is stated in the tenancy agreement he signed.

- Alexi has lived in an institution for 45 years, She shares a house on a campus with 7 other people. Alexandria has never been offered any alternative housing supports, advocacy or lifestyle options.

3. Safeguarding Case Study

Matthew lives in a house with 3 other people. Matthew becomes very upset at times resulting in him crying and screaming. On occasion Matthew's behaviour triggers others in the house to respond in a number of ways including in an aggressive manner resulting in safeguarding incidents being reported. While the outcome of these incidents is most often categorised as "negligible", they are occurring frequently over a long period of time and are having on the person's quality of life and the quality of life of other people who live in the house. The house is noted to be very noisy and there is little access to Day Services.

4. Use of mechanical restraints

- Martin's parents report that he started hitting his head aged 3 when he had an ear infection. Martin continued to hit his head throughout his childhood into adulthood. As an adult Martin would keep hitting his head until he knocked himself out. Staff were unable to support Martin safely using physical restraint due to his strength and the prolonged nature of the incidents. Staff request padded gloves to minimise the harm.

- Sean loves to get out into the community everyday. He has an active timetable and his own transport. Recently he began opening his seatbelt while the car was moving and distracting the driver. Staff used an angle guard to ensure his community outings continue and ensure his and the drivers safety.

- Martina uses a wheelchair for mobility. Sometimes Martina goes up to the fridge and helps herself to drinks and food. She can spill drinks and touch all of the foods in the fridge. She needs staff support to access food and drink safety. Some staff put the brakes on her wheelchair until they are ready to support her.

- Joe was assessed as having early cognitive decline. He can wake up disoriented during the night and leave his bed wandering the hallways. He has fallen out of bed twice this week and staff are concerned about his safety. They request bed rails to keep him safe.

- Susan can strip off her clothes in socially inappropriate situations. This can happen suddenly and frequently. To protect her privacy and dignity staff request an all-in-one suit.

- Sonia engages in eye pressing continuously throughout her day. Staff are concerned that her sight may be damaged. They request arm splits to prevent contact with her eye and preserve her eye sight.

5. Use of physical restraint

- Dan is a 28 year old man with an intellectual disability and a diagnosis of ASD. When distressed, Dan can bang his head with force against hard surfaces, for example, wall, floors, doors and may also punch a peer/staff. They staff team and family are concerned about Dan injuring himself may and others and they are now also querying whether it is safe to support Dan in the community. In the last month Dan has been physically restrained on two occasions. The team have requested behavioural support.

- Rebecca, a 22 year old lady is scheduled for a routine dental appointment. Staff and family are anticipating that she will need to be physically held in the dentist's chair. They have requested specific training on how best to physical hold Rebecca.

6. Environmental restraint

- Tom is a 37-year-old autistic man who lives in a group home with three other men. Tom drinks high volumes of fluids (e.g., water, milk, yoghurt). Staff recorded that Tom can drink on average of 11-12 litres of fluid per day and on one occasion up to 23 litres resulting in hospitalisation. When Tom is redirected from the kitchen tap, Tom may go to the bathroom and use a vessel to drink from the toilet. The staff team have been advised that it is medically unsafe for Tom to drink more than 3 litres of water each day.

- Ryan is a 38-year-old man who lives with one other man in a group home. Ryan has coeliac disease. Ryan cannot differentiate between gluten-free and foods with gluten. When Ryan ingests gluten, he can experience unpleasant physical symptoms for several days. Ryan finds it difficult to attend to visual supports. Staff are concerned for Ryan's health and have started to lock all kitchen cupboards.

- Ross can become emotionally distressed when in the car and may find it hard to regulate himself. Ross has hit out at staff with a closed fist and has also removed his shoe and threw it at the driver. Staff are concerned for both Ross's and staff's safety. They have queried whether they can have the car adapted to include a Perspex screen between Ross and the driver.

- Sam is an 18-year-old autistic man who has a severe intellectual disability. Sam recently moved into his own home, a single occupancy service, after a crisis at home where it was no longer safe for him to live with family members. Sam is supported by two staff. Sam is physically fit and strong. When he becomes distressed Sam shouts loudly, rips his clothes, throws his body against hard surfaces, punches his head with force, throws objects and hits out or pushes

anyone else in his space. Sam's team are committed to maintaining his safety and their own safety at time when Sam is acutely distressed. They ask him to go to the hall where Sam has access to his bedroom and bathroom and they lock the door until Sam has calmed down. Sam is unsupervised at these times and staff are concerned that he may hurt himself.

- Jane is a 30-year-old autistic woman who has a moderate level of disability. Jane lives in her own home, a single occupancy service and has full-time support from staff. Jane has a history of many placement breakdowns when she lived with other people in group homes. Jane has social anxiety and is hyper-vigilant when staff enter her space. Jane can suddenly become distressed and expresses this by screaming loudly and running towards staff to grab and to bite them. In the past staff have been hospitalised with injuries. Jane is hypersensitive to touch and the service prohibits the use of physical restraint. The team are concerned that Jane's stressors cannot be managed proactively and they are worried for their safety during these episodes of distress. They exit Jane's house and lock the door behind them until Jane has calmed.

- Mary is a woman in her 50s with a severe level of intellectual disability who does not use language to communicate. Mary has moved to her own home following many years living in a congregate setting. Mary has a life-long history of obsessive compulsive disorder. When she sees objects Mary will either throw them out or will ingest them. Staff want to promote Mary's independence in her new home while also maintaining her safety and well-being.

Section 4 Examples of restrictions

Environmental	Physical	Mechanical	Medication used as a Restriction	Human Rights Restrictions	Financial
• bed alarms; • pressure mats; • tracking device; • Bed Rails • epilepsy alarm mats; • infra-red door alarm; • locked presses; locked rooms; locked doors; locked kitchens/rooms; locked fridges; locked presses; locked offices in people's home; • lack of access to certain foods/drinks/ • access controlled to personal possessions (for example cigarettes); • specific diets (to include dysphagia related diets); • heavy doors (where the person does not have the physical strength to open it);	• physical holds- MAPA; physical holds to hand/arms; • Physically using body to 'Head off' – block or prevent a person's voluntary movement; • Holding limbs and head; • Low-level release holds (MAPA) • Use of force on mid back/elbow to direct a person to a certain area;	• Bed rails; • Bed bumpers • child lock-car(angel guard for example); • lap belts; • groin belts; • arm splints • gloves; • onesies- Body suits – children /adult services • transport vests • Helmet/cap/ head protector • 'Second Skin' for postural support • Chest Straps • Chest harness for travel on the bus • Limb splints and AFO's	• Suppression of menstruation/libido • PRN –chemical restraint- anxiety • Use of psychotropic medications in the absence of a mental health diagnosis; • The over-medication or misuse of medication • The long term use of medication without a review to reduce the use of medication for the purposes of behaviour management • Libido or menstruation suppression	• resource restraints- for example – lack of transport; lack of staff support for community participation; • campus based life; • peer to peer (safeguarding);restriction • restraint- lack of supports to leave the campus; • lack of access to day service and supports (to include discharged from day services and supports); • weight management programmes; • safeguarding concerns (peer to peer); • community access limited; • limits set on - drinks-fizzy drinks;alcohol, tea, coffee; • access to enjoyable activities restricted to once a week or once a	• financial limits; • no access own to money; • Money management programmes- collecting and monitoring spending; • Disability Allowance is collected and managed by a family member for one individual;

• doors that are disguised as bookshelves (with decorative wall paper); • 1:1 staff supervision (to prevent /limit) • sensor beams; • Perspex glass on a bus; • limits to environmental access- restricted with stair gates for example stairs/doors; • wheel chair used living in a two story house with no access to the upstairs; • seating plans on the bus /meal times; • codes on doors; • wheelchair access to certain areas of the environment is limited; • Wind chimes • Visual/auditory monitors • House alarms (to keep people in) ○ Food out of reach- (treats) • TV locked with no				month (swimming for example) • over encouraged to participate in an activity (for the benefit of the group) • support to have a relationship is limited or prevented;. • restrictions to apps/social media; • prevented from independent travel (family); • OCD treatment programme has restrictive practices in it; • staff inconsistency can cause restrictions to be put in place; • staff not available to support individual choices; • access to advocacy not facilitated; • Isolation • No driver on duty (no access to community – skill deficit) • Choices for daily activity reduced (to staff availability/resource/skill/	

free access; • Staff wearing arm guards • Scheduled toilet times (children) • doors locked and only accessible via key pads • Weighted blankets • Curfew; • Time for bed; and time to get up; • Industrial kitchen : access is restricted – service user kitchenette available for tea/coffee/snacks-cereal/toast/fruit etc. • Cigarettes; access is monitored and controlled; also spaces where smoking can occur are restricted; for example; bedrooms; (outside area is not weather friendly.) • Fire exit doors are all alarmed; and are used to monitor egress also(seen as a control measure) - especially				service deficits) • Lack of access to play station/ • Removal of phone chargers at night; • Removal of phones at night-time; • Restriction on accessing MDT services /waiting lists or no referral pathway • Family influence impacting on individuals being able to make their own decisions. • No alcohol allowed on the premises; • No overnight visitors permitted under the tenancy agreement • Clothes; limited /supervised access to clothes for one individual; with room locked where clothes are stored. • Search of personal bags; • access to communal spaces is controlled • no visitors after 9:30; • No access to housing support/options; • Children visiting their	

at night; • One individual's bedroom door was locked to prevent them from accessing it				parent; deemed not a 'safe place for a child'. Alternative place not always available.	