



#HSEConference2026

Integrated Healthcare Conference

Delivering Integrated Care Together

**Supporting Person-Centred Respite: Collaboration, Inclusion
and Impact in Disability Respite Services 2026**

Wicklow Hall 2, Convention Centre Dublin

3 September, 14:20 – 15:45



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Welcome and Introduction

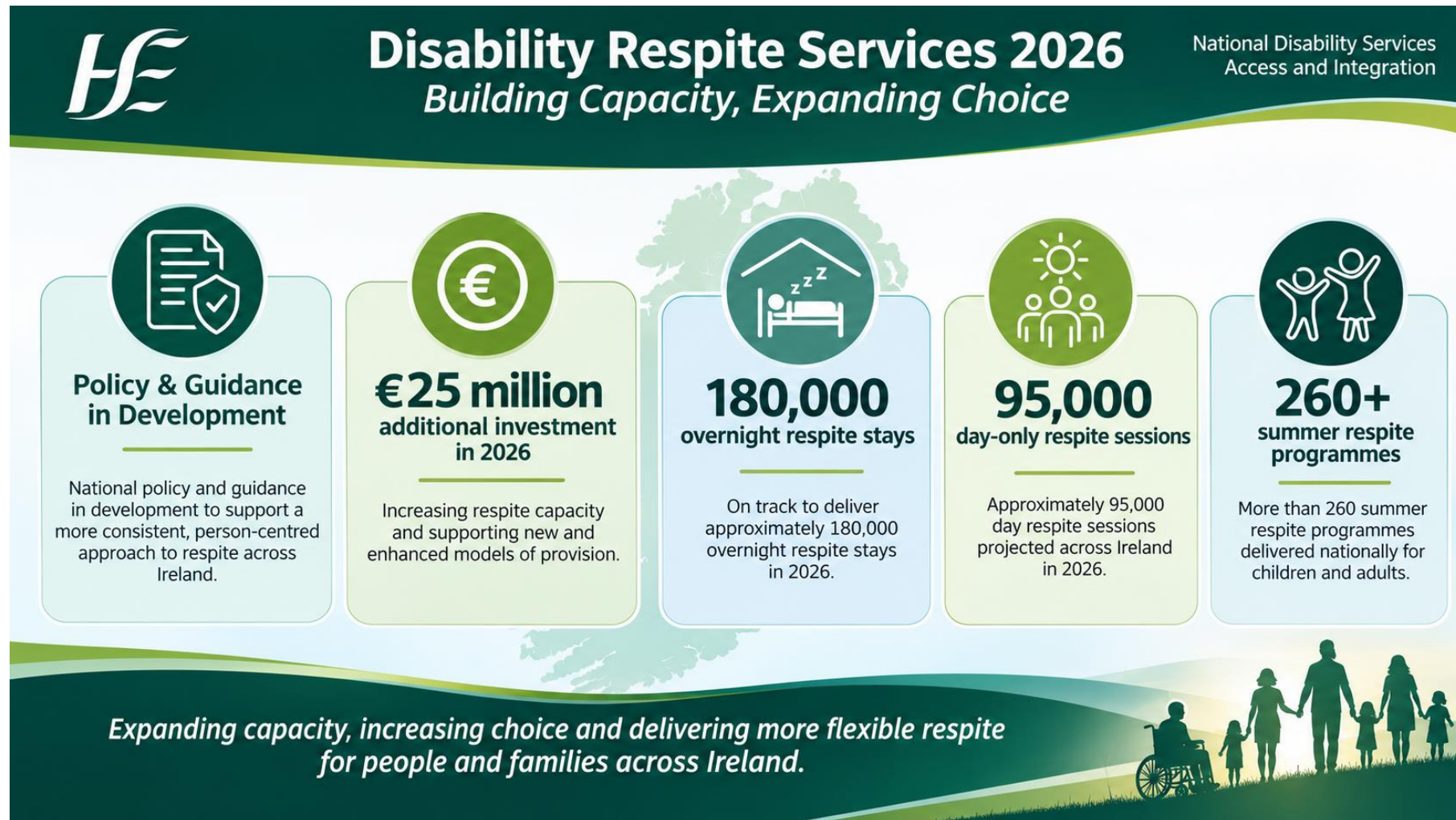
Bryan Dobson
MC



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Disability Respite Services 2026





Partnership in Practice



Recycle Mobility Programme

About the Programme

- Promotes Equal Access to Cycling for All
- Provides co-funding towards adaptive mobility trikes
- Offers inclusion, independence better physical and mental wellbeing
- Trikes receive a second life and donated to local schools
- Ongoing evaluation on this Programme is conducted in partnership with the RCSI University of Medicine and Health Sciences



Static Hubs

- Community based Inclusive Cycling Hubs offering free supervised access, with many hubs boasting dedicated cycling tracks
- Offers a range of adaptive trike, wheelchair transporters, hand-bikes and tandems

Mobile Hubs

- Bringing accessible cycling all around Ireland
- Offers free access to an large array of mobility trikes and inclusive cycling equipment



GAA All Stars Children's Inclusion Campus

- Free weekly sessions for all Dublin GAA All Stars children to come together for sport & fun
- Dedicated cycle track and adaptive trikes
- Sensory hub and sports hall on site

GAA All Stars Féiles

- Bringing accessible cycling all around Ireland
- Offers free access to an large array of mobility trikes and inclusive cycling equipment





Parents Experience

Emma Dooley O’Gorman



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A WORLD FIRST IN PWS CARE

Developing a Prader-Willi Syndrome Specific Respite Service

Sinead Butler

Interim Chief Operations Officer, Resilience Healthcare



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HE What is Prader-Willi Syndrome?

A rare, complex genetic condition — present from birth, lifelong, and highly individual in how it presents.



Chronic, insatiable hunger

Hyperphagia drives a constant physiological drive to eat, with no natural sense of fullness. Food security is a clinical necessity, not a preference.



Intellectual & developmental disability

Alongside PWS-specific traits such as low muscle tone, endocrine complications, and a need for structure and routine.



Behavioural & anxiety complexity

Uncertainty, unmanaged food access, or unfamiliar environments can quickly escalate to significant distress.



One of the rarest of the rare

Around 1 in 15,000–30,000 births - small numbers nationally, but intensive, specialist support needs.



How Common Is PWS in Ireland?

PWS is rare everywhere — and Ireland is no exception. Small national numbers, but every case needs intensive, specialist support.



Equal across sexes

PWS is not known to affect either sex preferentially - international research confirms it occurs at roughly equal rates in males and females.



Around 100 people in Ireland

An estimated 100 individuals are living with PWS in Ireland today (Gallagher et al., 2017, PWSAI/Trinity College Dublin).



5–6 new diagnoses a year

Ireland's National Centre for Medical Genetics - the only centre that tests for PWS - diagnoses roughly 5-6 new cases annually.



A minimum of 1 in 11,000 births

Based on that diagnosis rate - higher than global estimates of 1 in 10,000-30,000, likely reflecting strong case ascertainment here.



Specialist by Necessity, Not Preference

Why respite for PWS cannot be generalist

No natural safety net

“ The critical need for appropriate, PWS-specific respite services in Ireland... provision should be PWS-specific for consistency in management. ”

— Gallagher et al., 2017

Generalist services can't reliably lock down food access or routine

Zero margin for error

Families report that when generalist respite fails, it fails hard - increased stress at home, breakdown of food security, and a refusal ever to return.

A single failed placement can end a family's trust in respite for good



Specialist by Necessity, Not Preference



Two more reasons generalist respite falls short.

Informed workforce

The IPWSO Best Practice Guidelines for Standard of Care in PWS, along with guidance from PWSA UK and PWSA Australia, similarly recommend that residential services - including respite - be PWS-specialist, citing the need for a food-safe environment and “psychological food security.”

One parent's account: her son's respite placement failed because staff “did not understand PWS. They brought him to coffee shops, with no control over food. They could not lock kitchens as they were taking everyone's rights away.” The service wasn't negligent - it simply wasn't built for this condition.

The physical environment itself has to be different

The building must be designed around food security from the ground up: restricted access to kitchens and food storage, visual daily schedules, and a structured, predictable routine - what IPWSO calls “psychological food security.” Retrofitting good intentions onto the wrong building doesn't work.

— IPWSO, PWSA UK, PWSA Australia



Resilience's Research: Learning From the Best

In 2017, Resilience Healthcare travelled with members of PWSAI to Germany, Denmark and the UK to study established models of PWS-specific care.



Áit Shona, Official Opening

3

countries visited to
benchmark specialist
PWS care

Denmark alone runs ten specialist PWS services for a comparable population — proof that dedicated, specialist provision was both achievable and necessary.

In partnership with



Resilience
Healthcare

That research shaped Resilience's own PWS-specific model of care — and when the national Task Group visited Resilience's Lemongrove service, it was decisive: they saw first-hand why a specialist approach works, giving PWSAI the final push to secure HSE funding.

— on how the model of care evolved through direct experience, not a fixed blueprint

HE Building the Evidence Base

The respite service sits on the foundation of four PWS residential homes.



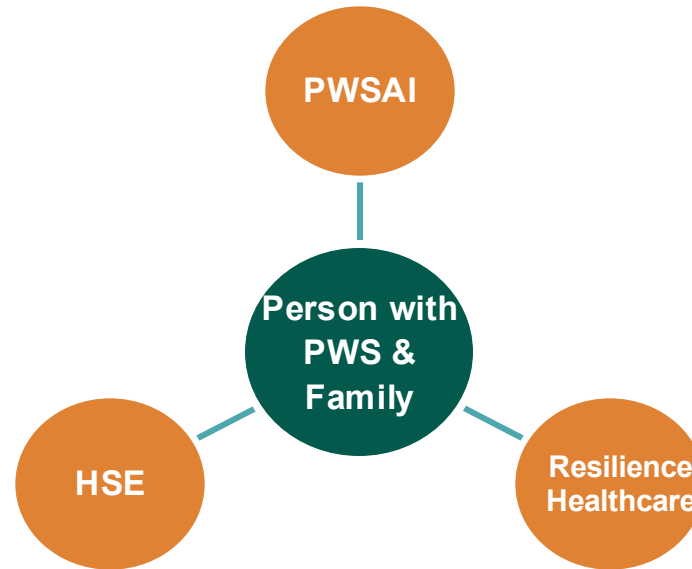
Four homes, one consistent PWS-specific model of care — the evidence base the respite service was built on.



A World First, Built on Collaboration

Áit Shona: the world's first PWS-specific respite service.

Voice of families. Drove the case
for equal, diagnosis-based
access — not crisis allocation.



Funding partner and clinical
governance, through NCPPD.

Delivery partner. Research-led
PWS-specific model of care.

PWSAI, the HSE and Resilience Healthcare co-designed the model together — with the person and family at the centre.

How Families Access Áit Shona

Equal access, by self-referral — not a crisis queue.

1

Self-referral

The individual can request a stay directly. No crisis or emergency trigger is required.

2

Eligibility check

Confirmed PWS diagnosis and assessed need. Access is based on diagnosis, not on how severe things have become.

3

Request to coincide with friends

Individuals ask to schedule their stay alongside friends met through PWSAI or previous visits, so peer relationships continue.

4

A planned stay

Booked like a holiday, with date certainty — something to look forward to, not an unplanned intervention.

Families say the ability to plan a stay around a friend's visit turns respite into something to look forward to — not something to dread.



How Families Access Áit Shona

Food security and structured routine translate directly into better health

Life-Changing

-  New friendships and social connection with peers who understand PWS-
-  Independence, confidence and new skills, built in a safe environment
-  A genuine break that gives families breathing room — a holiday, not a crisis



Life-Saving

-  Better overall health outcomes, through consistent food security and routine
-  Support for healthier weight management, reducing PWS-related weight gain
-  Reduced reliance on pharmaceutical intervention for behaviour and anxiety
-  Lower risk of the obesity- and food-related complications most associated with PWS mortality

36

individuals & families
currently supported

4

PWS-specific residential
homes now open

“ Mya has said that Áit Shona is like a home from home. She has really enjoyed spending time with other people who have PWS and making new friends. She said, ‘I don't feel so alone.’ ”

- Mya, and her family, on their experience of Áit Shona

What started as one family's story became a national model — proving that world-first, PWS-specific care is not just possible, but replicable.

Thank You



Enable Ireland Respite Service Initiatives

Gillian Darrer

Head of Services, South & West



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Enhancing Respite Services



Maximising
Capacity

Combining
Resources

Summer
Respite
Initiatives



Enhancing Respite Services

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Respite
Initiatives



Maximising Capacity in Residential Respite Services

What We Did

- 6 children's HIQA registered residential respite houses
- Moving from part time opening to opening 7/7
- Capital works to restructure layout - support those who need single occupancy arrangements

The Benefits

- Increased bed nights delivered
- Reduced the impact of those who need single occupancy
- No increase to number of designated centres = no increase in governance costs

Maximising Capacity in Residential Respite Services



- Move from 4/7 to 7/7 opening
- 500 additional bed nights each year
- 35 extra children and their families benefiting



Combining Resources – Packages of Care

What We Did

- Created efficiencies by combining packages of care
- Delivering from a single location
- One consolidated staff team and management

The Benefits

- Cost efficiencies
- Better oversight and governance
- Greater continuity of care for children and families





Combining Resources – Packages of Care

- Up to 1,400 bed nights
- Single occupancy apartment attached to 3 bedroom bungalow
- 1/3 of children getting weekly support leading to reductions in demand for fulltime residential placements

Summer Respite Initiatives

What We Did



- Took the learning from many years of providing summer camps
- Summer respite initiatives with different support levels to meet the varied needs of the children
- Looked away from the 'centre' and into the community

The Benefits

- New opportunities for fun and learning
- Community integration
- Cost efficiencies



Summer Respite Initiatives



- A variety of activities provided - surfing, equine therapy
- Targeted small groups working on functional goals - workshops for art, music, Lego, cookery
- Larger summer camp groups with a variety of community activities
- Sessions from 1 to 2 hours up to half a day
- Over 1,000 extra respite sessions provided





Rainbow Club Cork
Centre for Autism



RAINBOW
CLUB CORK
CENTRE FOR AUTISM





"Our mental health would have suffered without the structure & routine over the summer. Our kids badly need routine and structure. Thank you from the bottom of my heart. Much love and gratitude for all you do."

"Summer camps has 100 percent made our summer so much easier. D and C absolutely love coming down to Rainbow Club!"

"She has had the best summer ever. Thanks for all the amazing things ye did with them"

"L is finishing today and had a fantastic time, he loved it and keeps asking to go back!"

- Parents of Participant in our Summer Respite Initiative



Rainbow Club Cork

Centre for Autism



**RAINBOW
CLUB CORK**
CENTRE FOR AUTISM

Sports & Regulation

**RAINBOW
CLUB CORK**
CENTRE FOR AUTISM

“I had the best summer at Rainbow Club. I wish Rainbow Club was my school so I could come here every day!”

“My favourite part of summer camps was seeing my friends every day”

“I just want to thank you all so much. Camp really made a big difference to R's regulation. She thoroughly enjoyed it. And sibling camp was an absolute blast for C and a fab confidence builder ahead of his big school journey next week. We appreciate so much all your hard work”

Participant in our Summer Respite Initiative





Rainbow Club Cork

Centre for Autism



RAINBOW
CLUB CORK
CENTRE FOR AUTISM

Messy Play Activities

RAINBOW
CLUB CORK
CENTRE FOR AUTISM



“In previous years, we have dreaded the summer months, the lack of routine and support has detrimental affects on our family. The oppurtunities outside of the house for our son during summer are so limited because of his high care needs. Last year we ended up in A&E because we didn’t know where else to go; we had nowhere else to go. Rainbow Club’s Summer Camps has given us the necessary support this summer and we cannot thank them enough. Having this initiative funded through the HSE has alleviated so much financial pressure for us as a family. Thank you so much for all you do ”

“Our daughter has autism & an ID. We would pay all the money in the world for her to have a place where she is supported, accepted for who she is, cared for and happy, but thanks to Rainbow Club & HSE funding this summer, we don’t have to!

Parent of Participant in our Summer Respite Initiative





BEYOND THE CLINIC:

BRIDGING THE SUMMER FOR CHILDREN AND FAMILIES

Children's Disability Network Team
Galway Central and Galway City East



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Children's Disability Network Team



"A CDNT is a community-based interdisciplinary team that supports children with complex developmental, physical, sensory, intellectual, neurological and neurodevelopmental needs. Our focus is on maximising participation, function, development and family wellbeing in everyday environments such as home, school and community settings."



What happens when school stops?

“I dread the Summer coming”

“Even with July provision, August can be so long”

“There is nothing that is suitable for my daughter to attend during the Summer”

“I want him to have the same experience as my other children, to go to camps and meet other children over the Summer”

“I would love to have somewhere where I could bring all my children to, somewhere they could all enjoy”

“There’s no activities on that she can attend where she would be safe”



Could we bridge that gap?

Relationships

Knowledge & Expertise

Community



HE What did it involve?

Summer Club

Galway Community Circus Family Day

Galway Community Circus Camp

Introduction to Services

Summer Resource Pack



- Communication
- Movement
- Regulation
- Independence
- Choice Making
- Social Connection
- Participation
- Problem Solving



Function



Fitness



Fun



Friends



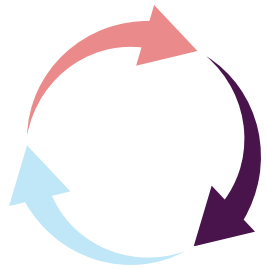
Family



Future



Participation
Integration
Community Inclusion



Partnership
Creativity
Funding





Where to from here?



“These were the first camps that we were confident to also include Adam and he had the best time! And for us parents, to have few hours for ourselves without kids knowing that they’re in best care, it was amazing. Also, it was great to see the people who we already know and are part of our family team. I hope it was also beneficial for them to get to know our kiddies even better.”

“The camps are an amazing support”

“She loved the break from home more settled when she come home”



“I’m grateful for those events it gives her a break and me”

“The camp was very beneficial for Sadie, she was immediately comfortable in familiar surroundings. I like that it was run by physio, SLT and CDNT team as it gave them a chance to observe her”.

“Any outing at all is most beneficial during the summer break, especially a camp where she can be independent of me her mother as most activities and entertainment has to be provided and organised by me”.





St. Josephs Foundation, Charleville

Liskennett Equine Assisted Activity Centre & Alternative Family Respite

Claire Mortell BSc(Hons)SLT MSc Person-Centred
Practice Interim Director of Clinical Services & Family Supports SJF



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From Service Model to Everyday Life

Alternative Respite Models

- In delivering funded models of care (CDNT/New Directions) -we are continually recognising unmet need through **listening to families**
- Families are **managing complex needs alongside everyday life pressures**
- Traditional respite and service hours do not always meet real family needs
- People need **opportunities to apply skills** learned in services to real-world, ordinary settings
- Highlights importance of **life outside a traditional service model** — supporting inclusion, participation, and family life.
- How do families access **meaningful support together**, in ways that reflect real life, beyond standard service hours?





Liskennett Equestrian Therapy Centre

Background

Established by SJF in 2015, Liskennett Equine Therapy Centre, Granagh, Co. Limerick is a national leader in Equine Assisted Therapy utilising the ‘Horseboy’ method.

Liskennett is unique-the physical design and concept lends itself to a much broader **equine-assisted, sensory, recreational, family-support and respite model**

Three interconnected strands:

- **Equine Assisted Activity Centre** – accessible to children and adults with disabilities, families, schools and external disability services. Open Access to families on Saturdays.
- **Adult Day Services** – supporting 24 adults and operating as a **New Directions Hub**
- **Adult Residential Services** – supporting 14 adults



Service Users (2025)	Schools (2025)	Service Providers (2025)
16,216	88	9



Liskennett Equestrian Therapy Centre

'Horseboy' Method

- The Horse Boy Method is a person-centred, neuro-affirming equine-assisted evidence-based approach that uses relationship, movement, motivation and the natural environment to create opportunities for regulation, communication, participation and learning
- Developed by Rupert Isaacson- Six-Stage Framework
- Learning, communication, emotional regulation and engagement are incorporated into interaction with the horse, movement and the natural environment
- Approach focuses on creating the right environment in which the person is **regulated, motivated and available for interaction and learning.**
- Outcomes relate to what is meaningful for the individual: **communicating choices, initiating interaction, shared engagement, self-regulation, participation, independence, confidence, learning and enjoyment.**



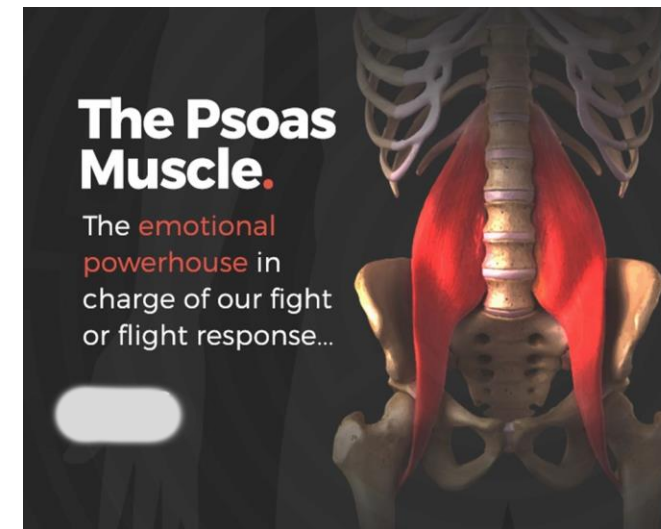


Liskennett Equestrian Therapy Centre

'Science and Research: How is learning, communication and regulation optimised?

- The **Horse Boy Method** proposes that the rhythmic movement of the horse, facilitated through supported riding, promotes physiological regulation that influences neuroendocrine systems associated with stress and social engagement, including oxytocin.
- **Oxytocin** is a neuropeptide involved in a range of processes including social affiliation, attachment, stress regulation and social behaviour.
- **Rhythmic movement** and a positive human-horse interaction increases oxytocin and therefore **reduces the stress response**, so the individual may enter a state in which they are **more regulated and socially available for learning**
- Western Saddle supports the rhythmic rocking movement of the rider's pelvis/PSOAS muscle produced by the horse's gait.

Horse's rhythmic movement → rhythmic rocking of the pelvis/hips → relaxation/regulation → reduced physiological stress → increased oxytocin → **greater readiness for social interaction, communication and learning.**





Benefits Of Equine Assisted Therapy

- Liskennett demonstrates how an equine facility can become a wider community and disability-service resource
- Optimum opportunity to integrate therapeutic goals with real life experiences
- Rethink service delivery outside of clinic based environments for neurodiverse learners

**Regulation → engagement →
shared attention →
communication → learning**



LISKENNETT
Equine Assisted Activity
CENTRE

Benefits of the Horse Boy Method

Using horses, movement and meaningful interaction to support communication, learning and wellbeing.



1. REGULATION & SENSORY EXPERIENCE

Rhythmic movement, outdoor activity and interaction with the horse provide a calming, predictable sensory experience.



2. COMMUNICATION

The horse creates natural reasons to communicate – requesting, directing, commenting, anticipating, making choices and interacting with others.



3. SOCIAL ENGAGEMENT

Interaction can be mediated through the horse, making engagement less demanding and supporting relationships at a comfortable pace.



4. MOTIVATION & ATTENTION

Activities are built around individual interests, increasing motivation, focus and willingness to engage.



5. LEARNING

Meaningful experiences support learning of concepts such as sequencing, numbers, literacy, following directions, problem solving and decision-making.



6. CONFIDENCE & AUTONOMY

Caring for, directing or riding a horse builds confidence, independence and a sense of achievement through real choices and successes.



7. MOVEMENT

Combines movement with communication and learning, supporting balance, coordination and body awareness in an active, enjoyable way.



The Horse Boy Method uses the power of horses and meaningful relationships to help individuals communicate, learn, grow and thrive.





Alternative Family Respite-Sundays: Building on what works

In 2025 new pilot for an alternative respite model was supported by the HSE — combining existing infrastructure and facilities on campus; with outreach from Liskennett Equine Centre, offering a day of activities that focuses on the **whole family**, in an inclusive setting

SJF responded to barriers faced by families:

- Opening services beyond typical working hours
- Open access for all families across the region who care for a person with a disability at home
- Inclusive, sensory friendly, no judgement
- Self-directed ethos to support flexibility and choice based on individual family need and interests
- No cost
- Open 26 Sundays in 2026 with **350 families from across Cork, Limerick, Tipperary and Clare** attended to date

Sunday at Fun Day St. Joseph's!
Family Respite Open Day

ALL FREE!

Looking for a happy, relaxed Sunday?
Bring the whole family for a day full of smiles, fun, and chill time!
For families with a child or adult with a disability and/or autism

WHERE? SJF, Bakers Rd, Charleville, Co. Cork, P56 KD26
WHEN? Sunday 21st June 2026
TIME? 9:00am – 3:30pm

BOOKING IS NOW OPEN! SCAN ME!

WHAT'S ON? (ALL FREE!)

- SPLASH TIME!** Jump into the pool! (booking needed – spaces are limited!)
- HORSE RIDING ADVENTURES** No booking needed – just hop on and enjoy!
- SPORTS & GAMES ZONE** Indoor hall + outdoor pitch + walking track
- PUTTING FUN** Mini challenges for all ages!
- MAKE NEW FRIENDS** Relax, chat, and connect in a warm, welcoming space! The Nest
- MUSIC THERAPY** with Anne-Marie
- PICNIC / SENSORY AREA** Come and enjoy the outdoors with your family

Come for a little... or stay all day!
It's your Sunday, your way!
If unable to attend, please cancel using the link in your booking confirmation email so families on the waitlist can avail of the slot

BOOKING REMINDER

sj CHARLEVILLE St. Joseph's Foundation

“Lovely atmosphere,
very welcoming”

“Well organised and
calm”

“Nice to meet other
families in a similar
situation”

“Our child loved the
horse-riding, it was a
highlight”

“Staff were very
patient and
supportive”

“A new experience for
our family and very
positive”

“Plenty of space and
time to enjoy
swimming”

“Great opportunity for
our child to enjoy the
pool without pressure”

“Having something we
can all do together as
a family”

“Being able to spend
time as a family in a
relaxed environment”

“A safe place where
our whole family was
welcome”

“The horse riding is so
calming for my son he
just adores it. This
facility is a blessing to
have access to”



Looking to the Future

Kanturk Equine Centre

- The **Kanturk Equine Centre** is a major new development-collaboration between SJF & HSE
- Kanturk project was conceived as a similar centre to Liskennett serving North-West Cork and the wider South West region.
- Broader than an equine centre alone: Plans for a **Regional Children's Respite & Residential Centre, Equine Therapy Centre**, Alternative Respite and accessible recreational/sensory facilities on one site
- **20,000** Equine Assisted therapy sessions per year
- **Employment opportunities** to the Kanturk area





Home Share Service

Western Care Association

Ruth Kneafsey / David Tuomey

Home Share Coordinator / Principal Social Worker

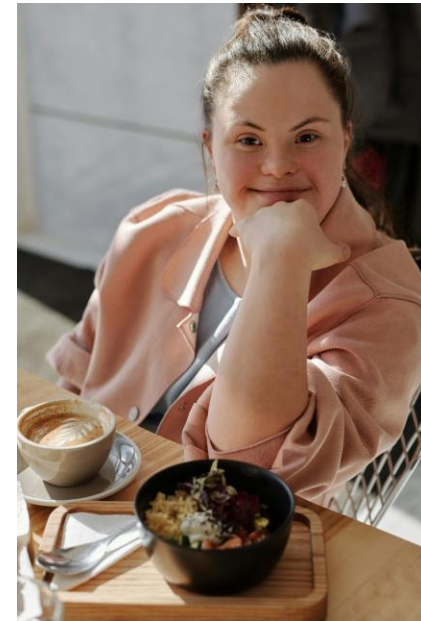


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Home Share – What is it?

- Home Share is a community-based initiative where pre-assessed individuals and families welcome people we support with additional needs into their homes and hearts for respite and long-term arrangements.
- A Home Share setting can be any household that provides short breaks, frequent breaks or full-time support.





Home Share – What is it?

- Home Share promotes community connections, individualised support and integration to realise the personal choices, goals, interests and dreams of the individuals we support.
- This transformative initiative creates lasting connections through genuine companionship and support, fostering a sense of belonging for everyone involved.





Aims and Objectives of Home Share



- To provide short breaks, frequent breaks, daytime and/or overnight stays or full-time support to adults and children.
- To provide 'natural' living options in the community.
- To provide regular breaks for the individuals family, ensuring the Home Share arrangement will be a positive experience for the person we support.
- To facilitate the community to provide a service to others and to experience the joy of welcoming the person into their own home and community, establishing fresh relationships and friendships.



Benefits for Those we Support Through Home Share

- Home Share is a person-centred service, and supports are tailored to the individual's needs and can also facilitate the individual's family to have private and personal time.
- Living and spending time within the Home Share family environment fosters social connections and personal growth.





Responsibilities of the Service Provider



- To support, oversee and grow the Home Share service:
 - Screening, assessments, matching and on-going supports and oversight.
- To support the person providing a placement (Home Sharer):
 - Training
 - Reviews & Supervision
- To support the person using the service:
 - Ensuring the Home Sharer has the knowledge and capacity to respond to the person's bespoke needs.

HE Benefits for the Home Sharer

- Welcoming somebody into their home and their family results in a deeper appreciation of diversity and understanding of difference.
- The emotional reward in supporting a person and their family, has the natural effect of an internal feel-good factor, achieved through the act of providing such an individualised human support service.
- Expenses covered and costs incurred vary depending on the needs of the individual.
- Working with a team and connecting with other home sharers.





Home Share Arrangements

There are 3 types of individual arrangements:

1. **Shared Living** – sharing your home full-time with a person requiring bespoke arrangements (we have a number of these shared Living arrangements in place).
2. **Respite Short Breaks** –the vast majority of requests for home share are for respite in the form of weekend, midweek and afternoon or evening breaks.
3. **Respite Frequent Breaks/Shared Care** - agree to provide a minimum number of home share sessions a month, with flexibility of the schedule.

This can be tailored to meet the needs of both parties factoring in work commitments and a person's preferences.

Western Care Association were delighted to receive funding from the Health Service Executive in the Summer of 2026 to further develop the Home Share Service.



45 home share arrangements are currently in place as of September 3rd 2026.



The 2022 National Census recorded a population of 138,000 in Mayo, equating to one home sharer for every 2,300 people. This places WCA as the number one service provider in the county based on home sharers per capita.



Autum Winter 2026/2027 - 7 additional arrangements are planned.



Spring Summer 2027 - 8 further additional arrangements to be developed.



Panel Discussion



Building a
Better Health Service
Care / Compassion / Trust

PANEL DISCUSSION

Working together for inclusive,
person-centred disability services



Care



Compassion



Trust





Thank You

Together, we are making a difference
for people and families across Ireland.

Thank you to all our partners, service providers
and colleagues who work alongside the HSE
every day to deliver high-quality, person-centred
respite and disability services.



Stronger
Together



Inclusive
Communities



Better
Outcomes

*Working together
for a brighter future* 



Thank you to the children and adults
with a disability **who inform the reform**
of how they want services to be delivered.



Your voice. Your choices.
Your life. Our commitment.

Go raibh míle maith agaibh
Thank you



#HSEConference2026

Conclusion of Breakout Session

Please proceed to The Auditorium (Levels 3 / 4 / 5)
for the Closing Ceremony

Next session commences
at 16:00



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