



ALL TOGETHER NOW

Creating a New Multispecialty Clinic in the Community for Children with Cerebral Palsy

Abstract

Children with Cerebral Palsy and similar conditions require multiple professional appointments in hospital and in community throughout their childhood. NHS Grampian staff look after these children across the NE of Scotland including Orkney and Shetland Islands spread over approximately 11,000 sq. miles. It is a challenge to offer accessible healthcare to this vulnerable patient group. In offering a community based multispecialty clinic closer to home we aim to improve patient care and family experience for those with complex healthcare needs whilst also reducing healthcare inequalities due to socioeconomic and geographic factors.

All together Now

Habilitation Integrated Community Clinic (HICC) for Cerebral Palsy

Authors:

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Introduction:

Children and young people with Cerebral Palsy and similar conditions require multidisciplinary input including Orthopaedics, Paediatrics, Physiotherapy and Occupational Therapy as part of managing their condition. These multiple appointments are time consuming requiring time away from school and employment for parents/carers. In the North East of Scotland the population is dispersed, it can often take 2 hours of travel or even an aeroplane journey to reach the Children's Hospital. The families get the impression of a disjointed approach, with multiple letters between clinicians/ therapists, delays and misunderstanding in communication and ultimately frustration for the family and delay in care for the child resulting in poor patient satisfaction.

NICE guideline on cerebral palsy (NG62) is clear about care pathways that should be accessible, with emphasis on early referral to an expert team for urgent multidisciplinary assessment, for care to be delivered by multidisciplinary and integrated local teams that can network other specialist services easily as required.

In 2021 we established 'one-stop shop' clinics to address these needs. The clinics are held closer to home/ school and not at the hospital. Both the hospital and community team (physiotherapist, occupational therapist, community paediatrician and orthopaedic surgeon) are present. This enables the family to convey their concerns and needs, for the child to be examined and for clinical decisions to be made with a multidisciplinary approach and enables families to have good simultaneous discussion with all of the specialists involved whilst reducing the number of appointments, administration, miscommunication and delays to treatment.

This approach is more time consuming (and therefore costly) for the healthcare providers; to ensure that it was meeting the proposed objectives and justified its' staffing cost we asked families for feedback of this new and evolving service and ideas on how we could improve it.

Goals for HICC clinic:

- Improve patient/family experience.
- Reduce the number of appointments per child.
- Reduce travel time and financial burden for families.
- Collaborative approach to optimising patient tone management.
- Improve inter specialty communication.
- Improve multidisciplinary approach to complex issues

Method:

- Creation of 9 HICC clinics across Grampian and the Islands
- Location of clinics; Aberdeen city (x3), Stonehaven, Inverurie, Fraserburgh, Elgin, Orkney and Shetland.
- Community Paediatrician, Orthopaedic Surgeon, Occupational Therapists and Physiotherapist attend each clinic.
- Patients with Cerebral palsy GMFCS 3-5 or equivalent with current complex clinical concerns needing a multidisciplinary approach are invited to attend. The appointment goal is to discuss medication, equipment and potential surgery to optimise the management of pain, tone, posture, activities of daily living, referral onwards to other specialties and address any other parental concerns.

Habilitation Integrated Community Clinic (HICC): Patient/Parent/Carer Feedback

All questions were same for both sets of data collected

First Data collection: 19 responses collected from 21st September 2021 to 31st October 2022.

Second data collection: 13 responses collected from 17th October 2023 to 14th June 2024

Our outcome measure included anonymised patient/carers feedback forms.

Results of Audit

N = 32 (19 2021/22 + 13 2023/4)

Clinic/Attendee Information

Q1 Which Child development MDT Team was your appointment with?

	Number (%)
Aberdeen City (Central)	6 (18.8)
Aberdeen City (North)	3 (9.4)
Aberdeen City (South)	1 (3.1)
Aberdeenshire (Inverurie)	11 (34.4)
Aberdeenshire (Fraserburgh)	3 (9.4)
Aberdeenshire (Stonehaven)	7 (21.9)
Not stated	1 (3.1)

Q2 Are you?

	Number (%)
A Patient	4 (12.5)
A Parent Guardian	28 (87.5)
Other	-

Q3 Which age group is your child/are you in?

	Number (%)
0 to 5 years	9 (28.1)
6 to 10 years	8 (25.0)
11+ years	15 (46.9)

Q4 Was this your first visit to this clinic?

	Number (%)
Yes	18 (56.3)
No	14 (43.8)
Not sure	-

Q5 Did the details provided within the invite letter, prepare you for this appointment?

	Number (%)
Yes	28 (87.5)
No	1 (3.1)
Not Sure	3 (9.4)

Please comment

2021-2022

- *No (Not first visit): I wasn't entirely sure what the HICC meeting was as such I was unprepared. But it was very useful to have the specialists all in one place at one time*
- *Not Sure (1st Visit): Very good valuable clinic, was not sure what to expect from letter*
- *Yes (1st Visit): The Directions of where to go were very clear. To an extent the letter prepared me but the appointment was so much better than I expected. I loved having everyone involved in Lily's care in one place*

2023-2024

- *Pre-discussed*

About the Appointment

Q6 Please indicate which of the MDT Team members were present at the appointment today? (Tick all that apply) Multiple response

	Number (%)
Community Paediatrician	29 (90.7)
Occupational Therapist	25 (78.1)
Orthopaedic Consultant	24 (75.0)
Physiotherapist	29 (90.7)
Other	4 (12.5)

Other 2021-2022 2 Comments

- School Doctor
- HIP Clinic

Other 2023-2024 Comments

- Orthotist/Prosthetist

Q7 Did you find it useful having all these professionals at one appointment?

	Number (%)
Yes	32 (100)
No	-
Not Sure	-

Q8 How comfortable did you feel about having this number of team members at the appointment?

	Number (%)
Very comfortable	28 (87.5)
Comfortable	4 (12.5)
Uncomfortable	-
Very uncomfortable	-

Q9 How comfortable was your child having this number of team members in the room?

	Number (%)
Very comfortable	21 (65.6)
Comfortable	5 (15.6)
Uncomfortable	1 (3.1)
Very uncomfortable	-
Not Applicable (Patient)	4 (12.5)

Q10 Was the length of the appointment....

	Number (%)
Too Long	-
About right	31 (96.9)
Too short	1 (3.1)

Experience at the HICC appointment today:

Q11 The team members

The team members...	Yes (%)	To Some Extent (%)	Not Sure (%)	No, not at all (%)	Not answered (%)
... were courteous and considerate	32 (100)	-	-	-	-
... explained things in a way I/we understood	32 (100)	-	-	-	-

... made me/us feel at ease	29 (90.6)	1 (3.1)	1 (3.1)	-	1 (3.1)
... listened to what I said /what we had to say	32 (100)	-	-	-	-
... treated me/us with dignity and respect	32 (100)	-	-	-	-
... gave me/us the opportunity to ask questions	32 (100)	-	-	-	-
...gave me/us the opportunity to discuss any anxieties	31 (97.0)	1 (3.1)	-	-	-
... involved me/us in decisions about future care	28 (87.5)	3 (9.4)	-	-	1 (3.1)

Q12 Were all your/your child's relevant needs addressed at this MDT clinic appointment?

	Number (%)
Yes	32 (100)
No	-
Unsure	-

Q13 Were you informed who to contact if you had any concerns or questions you may have, after this appointment?

	Number (%)
Yes	28 (87.5)
No	-
Unsure	3 (9.4)
Not answered	1 (3.1)

Q14 What went well at the MDT clinic appointment today?

2021-2022 15 comments

- *Absolutely fantastic idea, this reduces time away from work and school, reduces travel time and cost and reduces the stress and pressure on parents if ASN kids. I absolutely love the idea of seeing everyone at the same time because it improves communication between professionals about the child.*
- *All professionals know my son well. The appointment location was absolutely ideal, reducing travel time, disruption and stress.*
- *As I said before, having everyone there was so helpful. It went very well.*
- *First time with this type of multi meeting - great as things could be discussed between professionals there and then rather than there being a time delay.*
- *Good to see people face to face and reconnect, useful to have info shared*
- *Having all the professionals together locally is a huge help to agree a way forward with care*
- *Having all the specialist in one room to discuss issues and future concerns.*
- *Information was shared and a plan made*
- *It was fantastic to have everyone in the same room.*
- *It's good to have everyone in one place in discussion at the same time.*
- *Joint thinking, good opportunity to hear and discuss patient and professional*
- *Really good having all of the relevant health care professionals in one room, to discuss issues and care and agree a plan of action. Rather than have separate appointments and reports written. It was clear that everyone in attendance had read the relevant reports and were up to speed, which meant less preamble and repetition was required. It was also good that it was held in Inverurie rather than RACH.*
- *The doctors were very thorough and friendly.*
- *Very informative and all our issues discussed. Felt listened to. Felt Professionals were really trying to help.*
- *We liked the idea of seeing all professionals together and being able to have a discussion around daughters care/ problems.*

2023-2024 11 comments

- *All discussions and review from all medical professionals*
- *A good plan was put in place for my son*
- *All the needs were discussed*
- *Being able to share information about my daughter condition and progression together and work together*
- *Concise and clear advice about future of my son's life. Need to see how his CP will develop and change with time and growth as well as interventions and treatment available*
- *Everyone was happy with my progress*
- *Explanation of meds to be introduced Next steps CIPPS update*
- *Professional and Care of my son was at the front of the Agenda. Loved to speak and take an interest in him*
- *Reassurance, Referrals and Information*

- *The entire appointment was satisfactory*
- *Useful to have everyone in the same room to discuss issues and plan*

Q15 What did not go so well at the MDT clinic appointment today?

2021-2022 10 comments

- *I was told someone would call me and then come outside and get us. This didn't happen so we were late as sat in car park for 15 minutes.*
- *It was too short. Too much time was spent assessing the child when we attend CPIPS for this reason.*
- *My daughter had her CPIPS clinic a month ago, but the report was not available for the doctors for this appointment. So I had to relay how the CPIPS went to the doctors.*
- *N/A*
- *Nothing x 3*
- *Nothing. All great*
- ***Patient:** Alright but slightly overwhelmed by so many staff, but this is 1st clinic and lots of new faces. Also big issues need to be talked about.*
- *Perfect appointment - started a little late but I'm still delighted because I saw four professionals at the same time.*

2023-2024 7 comments

- *N/A x2*
- *None*
- *Not applicable*
- *Nothing*
- *Nothing*
- *Nothing it was good*

Q16 What do you think could be improved at the MDT clinic?

2021-2022 10 comments

- *As this was our first time attending this clinic we were quite happy with the*
- *Keep up clinic way it went. Not sure if anything needs improving.*
- *Just appointments - involve other departments where possible, epilepsy, nurse just whoever needs to see kids regularly! Height and weight check for records might be a good idea.*
- *N/A*
- *Nothing x 3*
- *Opportunity for parent to talk in private with team (just a few mins)*
- *Relevant information being made available and on time for the MDT clinic*
- *Social work to be involved for a holistic approach*
- *The Physio and OT that know and work with my child to be there.*

2023-2024 4 comments

- *Thanks for all your help and support over the years*
- *Not Applicable*

- *Not Applicable*
- *Everything is fine*

Q17 Please feel free to add any additional comments you may have:

2021-2022 7 Comments

- *A great idea to have several professionals all together*
- *Brilliant to cut lots appointments and travel by having everyone together and closer to home. We live in rural North Aberdeenshire, so this is a big problem generally.
Data Entry manually by QIAT. Appears although Patient responding was ticked, input from Mother as well as Child. Child Very Comfortable and Mum "somewhere in between Comfortable and Uncomfortable having this number of team members at the appointment - "different emotions"*
- *I think this clinic is a great idea; especially since I can't drive. Having one appointment instead of several makes so much more sense.*
- *Otherwise, I think its great getting to see everyone involved with my daughter at the same appointment.*
- *Really appreciate a more local service - much less stressful for us all. Feels great to see all 4 professions working together to find the right solutions for my child.*
- *Thank you to all for their continued support*
- *This is the best idea ever, it will improve services for the patients no end, it will free up parking at RACH which is always an issue it's brilliant to have these locally.*

2023-2024 5 Comments

Comment from parent:

- *Very pleased*
- *Not Applicable*
- *Not Applicable*
- *Depending upon what needs to be discussed it can be overwhelming having so many people in the room/difficult to process so much info. But also very useful to have everyone on the same page and reduce number of appointments and travel required.*

Comment from patient:

- *It is brilliant having everyone together. I have got more used to these kind of appointments and meeting everyone isn't so scary. Q9 Still a bit overwhelmed but getting better*

Summary of Result:

- 100% found it useful having multiple professionals at single appointment.
- 100% were comfortable with the number of people in the room.
- 97% agreed appropriate appointment length.
- Appointment location was local therefore reducing travel time, disruption and stress for all.
- Parents/carers found it very useful to have all relevant professionals at one appointment.
- All their relevant needs were addressed and plans made through collaborative joined up discussion regarding current and anticipated issues.
- The overall experience was extremely positive.

Conclusion:

- Feedback from audit suggests improved patient experience and quality of care.
- Professionals benefit from improved collaborative working.
- Collaborative working pattern of specialists is essential to provide best care for this group of children.
- These findings could inform the future provision and care delivery of services for this population in the form of involving other specialities such as Orthotics, Dietetics, Speech and language therapy and Gastroenterology.

Acknowledgement to the following teams:

Community Child Health (gram.cchop@nhs.scot)

Paediatric Orthopaedic Surgery (gram.rachorthopaedics@nhs.scot)

Paediatric Occupational Therapy (gram.childrensoccupationaltherapy@nhs.scot)

Paediatric Physiotherapy (gram.cdtphysiotherapy@nhs.scot)

Quality Improvement and Assurance Team (NHS Grampian)

References:

NICE guideline on cerebral palsy (NG62)

Questionnaire



Habilitation Integrated Community Clinic: Patient/Parent/Carer Feedback Questionnaire

Having attended the multi-disciplinary team (MDT) Habilitation Integrated Community Clinic (HICC) today, we would appreciate it if you would complete this questionnaire, which provides you with the opportunity to tell us about your experience. Please be as honest and as open as possible, so that we can continue to improve the service we provide. The information you provide is confidential and anonymous. We will not be able to identify you from your responses.

Clinic/Attendee Information

Q1	Which Child development MDT Team was your appointment with?																		
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Q2	Are you?																		
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Q4	Was this your first visit to this clinic?																		
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Q5	Did the details provided within the invite letter, prepare you for this appointment?																		
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Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not sure	<input type="checkbox"/>														
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About the Appointment

Q6

Please indicate which of the MDT Team members were present at the appointment today? (Tick all that apply)

Community
Paediatrician..... ☐

Physiotherapist ☐

Orthopaedic
Consultant..... ☐

Occupational
Therapist..... ☐

Other..... ☐

Other please specify

Q7

Did you find it useful having all these professionals at one appointment?

Yes..... ☐

No..... ☐

Not sure..... ☐

Q8

How comfortable did you feel about having this number of team members at the appointment?

Very comfortable..... ☐

Comfortable..... ☐

Uncomfortable..... ☐

Very uncomfortable.... ☐

Q9

How comfortable was your child having this number of team members in the room?

Very comfortable..... ☐

Comfortable..... ☐

Uncomfortable..... ☐

Very uncomfortable.... ☐

Not applicable..... ☐

Q10

Was the length of the appointment

Too Long..... ☐

About right..... ☐

Too short..... ☐

Experience at the HICC appointment today:

Q11

The team members

Yes

To some extent

Not sure

No, not at all

Were courteous and
considerate

☐☐☐☐

Explained things in a way
I/we understood

☐☐☐☐

Made me/us feel at ease

☐☐☐☐

Listened to what I said/what
we had to say

☐☐☐☐

Treated me/us with dignity
and respect

☐☐☐☐

Gave me/us the opportunity
to ask questions

☐☐☐☐

Gave me/us the opportunity
to discuss any anxieties

☐☐☐☐

Involved me/us in decisions
about future care/

☐☐☐☐

Q12 Were all your/your child's relevant needs addressed at this MDT clinic appointment?
Yes ☐ No ☐ Unsure ☐

Q13 Were you informed who to contact if you had any concerns or questions you may have, after this appointment?
Yes ☐ No ☐ Unsure ☐

Q14 What went well at the MDT clinic appointment today?

Q15 What did not go so well at the MDT clinic appointment today?

Q16 What do you think could be improved at the MDT clinic?

Q17 Please feel free to add any additional comments you may have:

Thank you for taking the time to provide feedback on your experiences at this clinic.

The HICC MDT Team