COLLECTING STANDARDIZED AND MEANINGFUL FEEDBACK FROM YOUTH AND FAMILIES

Presenters:
Catherine Ahern, Manager of QI and Evaluation
Laura Duncan, Researcher
Louise Murray-Leung, Family Engagement Lead
Nancy Rumble, Core Service Provider
Facilitator: Al Cudmore, Implementation Specialist
Agenda

1. Background & Context – Catherine
2. Service Area & Lead Agency – Catherine
3. System Level & Research – Laura
4. Engaging Youth & Families – Louise
5. Core Service Provider Implementation – Nancy
6. System & Research Implication Workshop – facilitated by Al Cudmore (CAMH)
Agenda

- Part 1: Background & Context
- Part 2: Service Area & Lead Agency Perspective

Lynwood Charlton Centre, Lead Agency for the Hamilton Service Area since 2014
# About Hamilton

![Map of Ontario with Hamilton highlighted]

<table>
<thead>
<tr>
<th>2016 Census</th>
<th>Hamilton</th>
<th>Ontario</th>
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<tbody>
<tr>
<td>Pop</td>
<td>536,917</td>
<td>13,448,494</td>
</tr>
<tr>
<td>Avg. Age</td>
<td>41.3</td>
<td>41.0</td>
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</table>

About Hamilton
Percentage children falling below Low Income Measure by FSA, 2009

FSA: Statistics Canada Forward Sortation Area (Grouped Postal Codes)
Child/Youth Mental Health (MH) Services in Hamilton

- Lynwood Charlton Centre is the Lead Agency (LA) - Children’s Mental Health Service

- 13 MCCSS Children’s Mental Health providing agencies in total, including…
  - small focused-service agencies
  - small MH programs embedded in providers of a range of services
  - large MH providers embedded in health services

- All Core Services are available in Hamilton, from Brief Counselling, Crisis to Residential
Child and Youth Mental Health Services in Hamilton

- A wide range of client feedback needs!
  - Highly variable populations
  - Clients’ capacity and interest to provide feedback also varies, given the wide range of populations served

- Benefits and complications to such variability!
The Challenge

• How do we create comparable service area level data to capture what “counts” as a positive experience?

• In other words...
How we get ‘apples to apples’?

Does
Plan for heading in the *same* direction

- **Shared Vision**…
  - We know we will never get to an ideal state
  - Developed a shared vision of our future state
  - No single ‘right way’; just hoping to be heading in the same way 😊
“Develop a brief standardized tool to gather direct parent/caregiver and youth feedback about their experience of service within the Hamilton Service Area”

- Parent/caregiver: can include parents, foster parents, grandparents, child welfare worker ... anyone who knows the child or youth very well
Why re-invent the wheel?

- We completed a thorough review
- Many tools were too long or out of date
- Most were focused on the ‘satisfaction with care’ rather than the ‘impact of care’ and ‘experience of care’
- Nothing was versatile enough for the wide range of settings, client needs, and provider capacity
- Not well suited for children

**Most important reason:**
Nothing captured needed Ministry key performance indicators!
Our process – simplified

1. Identify need for service area approach
2. Ensure appropriate representation
3. Literature review & environmental scan
4. Start with existing agency form
5. Consult with youth & families
6. Test & revise
7. Finalize Feedback Form
8. Develop staff user manual
9. Implementation
10. Review and Revise

Review and Revise
Easy to get lost trying to capture data that is meaningful and simple!

Road to “Meaningful” data...
- Valid
- Useful
- Reliable
- Relevant

Pitfalls:
- Challenging to collect
- Confusing to analyse
- Irrelevant information
Signposts to follow to stay on the path to the “Future State”!

- **Forms**
  - Direct feedback for both parent/caregivers and youth
  - Comparable AND flexible
  - Easy to use
  - Applicable

- **Related Processes**
  - Easy for workers to support completion
  - Analysis instructions
  - Useful at a program, agency, and system level, as well as meet Ministry requirements
Where we ended up:
Hamilton Service Area Feedback Form

- Youth and Caregiver, Regular & Brief Versions
- 8 simple Likert-scale Questions
- Freestanding, or can be incorporated into existing feedback processes, or can be added to (Lynwood has an additional 4 experience of care questions)
- Simple to use on paper or publish in an electronic version (e.g. SurveyMonkey)
- 4 translations
### What are we trying to measure?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Legend</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am having an easier time coping with my feelings.</td>
<td>#CPOSOOC</td>
</tr>
<tr>
<td>I am having an easier time managing my behaviours.</td>
<td>#CPOSOOC</td>
</tr>
<tr>
<td>Daily activities are easier for me.</td>
<td>#CPOSOOC</td>
</tr>
<tr>
<td>My treatment was well planned.</td>
<td>#CPOSEX</td>
</tr>
<tr>
<td>I was involved in planning my treatment.</td>
<td>#CPOSEX</td>
</tr>
<tr>
<td>Most of my treatment goals were met.</td>
<td>#CPOSOOC</td>
</tr>
<tr>
<td>I waited a reasonable amount of time to get help.</td>
<td>#CPOSEX</td>
</tr>
<tr>
<td>I was supported to get help from other places. (Leave blank if not applicable.)</td>
<td>#CPOSEX</td>
</tr>
</tbody>
</table>

Legend for providers to inform their Ministry KPIs.
Feedback Manual: Agreeing on which way is “North”

- Remember... goal was to choose “same” way, not the “right” way, for 13 agencies
- Offered guidance about many aspects of using the Feedback Form, including
  - Who (e.g. caregiver, youth?)
  - When (timing)
  - Confidential or anonymous
Caregiver or Youth Forms?

- Pros and Cons to both options
  - Caregivers tend to provide more positive feedback
  - Youth are the individuals most directly affected by care because they’re usually the ones in service

- We ended up with some “granny smith” to “macintosh” options!
  - It is up to individual agencies to decide
Timing

- When to Ask? Consistent approach/ flexibility with timing
  - e.g. All the way through or right at the very end?

- End of service, if you can!
  - Encouraged Hamilton service area agencies to ask near to end of service to complete the form
Confidential vs. Anonymous

Cons

- Greater risk that caregiver/youth may not share completely or honestly
- Greater risk that caregiver/youth refuse to complete survey

Pros

- Shorter – saves from asking demographic & service history questions
- Better response rates
- More reliable mapping to service history (not relying on clients’ memories of their services)
No evidence that confidential had a negative impact!

- Wide range of responses in the Lynwood Charlton Centre & Thrive data; some of it painfully honest!

- Clients stated it wasn’t a problem in testing:
  - Reviewed with 18 caregivers & 13 youth
  - Most of the comments were that it wasn’t a problem
    “They would already know my name if they were already working with me.”
Lynwood Charlton Centre’s Experience as Service Provider

- 1 year of in house pilot of an early version
- 1 year of trialing draft Hamilton Service Area Feedback Form
- Over 1 year of fully implementing feedback form (since April 2017)
- Improved completion rate
- One comment from a staff member (form is not well suited for youth with mild intellectual disability), but suggestion in manual for helping in this situation.
Lynwood Charlton Centre Data

<table>
<thead>
<tr>
<th>Year</th>
<th>Caregiver</th>
<th>Youth</th>
<th>Total</th>
<th>Response Rate</th>
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<tbody>
<tr>
<td>2016-2017</td>
<td>86</td>
<td>34</td>
<td>120</td>
<td>60%</td>
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<tr>
<td>2017-2018</td>
<td>76</td>
<td>36</td>
<td>112</td>
<td>66%</td>
</tr>
<tr>
<td></td>
<td>162</td>
<td>70</td>
<td>232</td>
<td>63%</td>
</tr>
</tbody>
</table>
3. A system level & research perspective

Laura Duncan
Research Coordinator & PhD Candidate
Offord Centre for Child Studies
Standardized & meaningful feedback from youth and families is about...
A system-level & research perspective
A system-level & research perspective
DATA

- **Good quality**: valid, reliable, complete, standardized

- **Meaningful**: self-report, purposeful, actionable, timely

- **Useful & used**: to inform & improve practice & service, meet reporting requirements

- **Sharable & shared**: to government, administrators, staff, families & youth
DATA

- Lack of standardized measurement or administrative data in Ontario

- Investing in a ‘system of care’: useful to individual agencies, service area & system

- Accountability: doing the best we can (service-oriented)
DATA

- **Agency level:**
  - Meets reporting requirements
  - Service planning
  - Understanding basic client needs & outcomes

- **Service area level:**
  - Service planning
  - Understanding basic client needs & outcomes across service types
  - Decision-making

- **Provincial level:**
  - Standardized administrative data
  - Inform planning & policymaking
  - Make performance indicator data useful
• Agency level:
  - Meets reporting requirements
  - Service planning
  - Understanding basic client needs & outcomes

• Service area level:
  - Service planning
  - Understanding basic client needs & outcomes across service types
  - Decision-making

• Provincial level:
  - Standardized administrative data
  - Inform planning & policymaking
  - Make performance indicator data useful
• Individual agencies & lead agencies are leading the way

• Staff, leadership, family, youth, & researchers
DATA

• **Navigate constraints:** legislative, political, respondent & clinician/staff burden, usefulness

• **Through service area collaboration**

• **Co-development:** We’ll share our experience
Thank You

Questions/Feedback?

Contact Laura Duncan (duncanlj@mcmaster.ca)
What does the data look like?

• Average scores overall and for parent/caregivers and youth separately

• Code missing data and decide how to handle it

• What to do with unclear responses?

• Use formula in Excel or a statistical software program (e.g. PSPP is free)

• Response rates?
<table>
<thead>
<tr>
<th>Category</th>
<th>Average score Mean (SD)</th>
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<tbody>
<tr>
<td>Satisfaction</td>
<td>4.61 (0.84)</td>
</tr>
<tr>
<td>Staff were understandable</td>
<td>4.77 (0.51)</td>
</tr>
<tr>
<td>Staff listened</td>
<td>4.74 (0.58)</td>
</tr>
<tr>
<td>Staff were kind</td>
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</tr>
<tr>
<td>Staff were kind to my child</td>
<td>4.70 (0.67)</td>
</tr>
<tr>
<td>Coping with feelings</td>
<td>4.15 (0.96)</td>
</tr>
<tr>
<td>Coping with behaviours</td>
<td>4.07 (0.96)</td>
</tr>
<tr>
<td>Easier daily activities</td>
<td>4.08 (0.93)</td>
</tr>
<tr>
<td>Well planned treatment</td>
<td>4.44 (0.85)</td>
</tr>
<tr>
<td>Involved treatment planning</td>
<td>4.51 (0.79)</td>
</tr>
<tr>
<td>Treatment goals met</td>
<td>4.02 (1.02)</td>
</tr>
<tr>
<td>Wait time</td>
<td>3.96 (1.24)</td>
</tr>
<tr>
<td>Transition support</td>
<td>4.45 (0.88)</td>
</tr>
</tbody>
</table>

n=232 (parent=162 youth =70)
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n=232 (parent=162 youth =70)

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**n=48 parent/youth dyads**

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<th>Average youth score</th>
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<td>Staff listened</td>
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<td>4.89</td>
</tr>
<tr>
<td>Staff were kind</td>
<td>4.60</td>
<td>4.93</td>
</tr>
<tr>
<td>Staff were kind to my child</td>
<td>4.33</td>
<td>4.93</td>
</tr>
<tr>
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<td>4.30</td>
<td>4.15</td>
</tr>
<tr>
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n=48 parent/youth dyads

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<thead>
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<th>Parent-youth agreement</th>
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<td>.55 **</td>
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<td>.34 *</td>
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<td>.25</td>
</tr>
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<td>4.33</td>
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<td>-.01</td>
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<tr>
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<td>4.21</td>
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<td>.62 **</td>
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<td>.36 *</td>
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<tr>
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<td>-.26</td>
</tr>
</tbody>
</table>

*p<0.05, **p<0.01, ***p<0.001
Data considerations

• How many people were eligible to complete a form? How many actually did?

• Is there a lot of missing data? Is there anything you can do about that?

• Were all response options used?

• Do scores vary by program or service? Time of year?

• Summarise results to staff & families (e.g. waiting room poster, staff newsletter)
Stand & Stretch!
Engaging youth & families

Louise Murray-Leung
PCMH Hamilton, Chapter Leader
hamilton@pcmh.ca

Family Engagement Lead, Lynwood Charlton Centre
lmurray-leung@lynwoodcharlton.ca
What is family engagement?

Family engagement is an ongoing process that includes families as active decision-makers and equal partners in treatment/service delivery at the individual, organization and system levels.

Meaningful family engagement is often described by families as feeling heard, being valued for the unique knowledge and expertise they bring, sharing in dialogue and decision-making, and knowing that their contributions make a difference.
Engagement as a continuum

HART’S LADDER

- Partnership
- Co-development
- Consulted
- Informed
- Tokenism
- Decoration
- Manipulation

Lynwood Charlton Centre
Why engagement?

• **System level engagement** of youth and families is a commitment of our service area.
  - Getting to a system that works better for children, youth and families is more likely when those accessing service are part of planning
  - Positioned for family engagement (FE) at that time

• **Meaningful engagement in evaluation** is possible and beneficial at all levels – individual, organization and system.
  - Youth and families who believe the feedback they provide has an impact are more likely to share - and share honestly
Why engagement?

• Bringing **family voice** into the development of the feedback form and its accompanying manual **helped ensure that barriers and facilitators** to gathering quality data **were considered prior to implementation** across the service area.
  - *Improved language – form description, question wording and layout*
  - *Addressed providers concerns around confidentiality vs. anonymity*
  - *Ideas for when and how to introduce feedback form*

• **Meaningful co-development** and **consultation** with families created opportunities to improve completion rates and data quality as well as build capacity for engagement.
  - *Better process – youth and family perspectives keep us centred*
  - *Better product – easier to understand and more accessible*
  - *Better quality data – more accurate reflection of services (↑ validity)*
Who to engage?
And when?
Who to engage? And when?

Include families as equal members on committee or work group:
- Providing insight
- Sharing in decisions
- Engaging other families

Who to engage?
And when?

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Who to engage?
And when?

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Who to engage?
And when?
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Reach out to more families for input, feedback and testing:
- Existing advisories/committees
- Local family groups like PCMH
- Families accessing service
- Distribution lists

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Let the broader community know about the work accomplished with families:
- Newsletter
- Website
- AGM reports
- Community table updates
- Knowledge sharing

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- Distribution lists
Facilitators for engagement in our process

• Service area level commitment to family engagement (priority, resources, $)
• Openness of group members
• Family member had good understanding of our local system AND family engagement principles
Facilitators for engagement in our process

- Partnerships
  - Hamilton Service Area Core Service Providers
  - Parents for Children’s Mental Health (PCMH), Hamilton Chapter
  - McMaster Children’s Hospital – Offord Centre for Child Studies
  - McMaster University – Office of Community Engagement
  - The Centre for Addiction and Mental Health (CAMH)
Barriers/challenges to engagement

• New area and scope for FE in our area
• Uncharted territory – FE evidence is often limited to individual or organizational contexts
• Balancing family and agency perspectives/concerns
Barriers/challenges to engagement

• “Meaningful” had dual contexts:
  • what is meaningful data?
  • what is meaningful FE?

• Timelines – always short!

• Limited resources – unable to maximize engagement opportunities

• Limited access to youth and family voice from various/diverse communities
Engagement - lessons learned

What worked well

- Family representation in planning groups
- Ensuring adequate knowledge & context
- Partnering to augment youth and family voice
- Engagement training experience
- Two-way communication
- Validating all perspectives
- Acknowledging competing priorities
- Follow-through on input
- Continuously asking ourselves what does or does not work for families and youth
Engagement - lessons learned

Considerations for the future

• Make engagement more intentional
• Be clear/realistic about limitations
• Engage youth from the beginning
• Include youth representation on the work group
• Better engage diverse youth and families
• Create shared decision-making processes
• Involve youth/families in supporting staff engagement (ex. information session for form and manual)
• Explore and utilize engagement resources (next slide)
• Engagement done well is messy!
Useful engagement resources

Engagement Action Plan

Connecting Hart's Ladder of Engagement with Decision-Making Processes

Star of Youth Engagement

Hart's Ladder

Things to think about:

- How the process works (how often is movement within the steps)
- What decisions need to be made and why?
- What decisions can be made?
- What are the implications of these decisions?
- What kind of support is needed to make these decisions?
- What level of engagement would be anticipated at each stage?
“If it doesn’t work for families, it doesn’t work at all.”

“Youth engagement makes everything better!”
THANK YOU
Helping Children Thrive

Nancy Rumble MSc, MSW, RSW
Clinical Social Worker
5: Core Service Provider Implementation

- Our Service
- Considerations for Implementation
- Implementation Process
- Benefits
- Our Feedback Forms
- Our data
We believe thriving children create thriving communities

Our Service

SAAT

OASIS
Considerations for Implementation

- Telling a community story without losing our agency’s story
  - Specialization
  - Historical data collection

- Extensive existing data collection
  - Assessment psychometrics, as well as outcome data

- Multiple languages

- Small agency
Implementation Process

1. Agency Perspective
2. Clinical Perspective
3. Client Perspective
Benefits

• Opportunity to evaluate existing feedback forms
  – Process
  – Data collection

• Flexibility in administration of feedback form

• Translated versions provided at no additional cost

• Valuable additional data points
Client Feedback Survey  
Youth Form  
(Ages 12 years old and up)

Your experiences with our service matter and your feedback will help others. The information you share will help us learn what we do well, and how we can improve. All the responses we receive, including yours, will be combined into summary reports. These reports do not identify anyone.

This survey is voluntary and will not impact the services you receive at Thrive. This form will take about 5 minutes to complete.

I was involved in the Sexual Abuse Assessment and Treatment Program because of my
☐ sexual abuse  ☐ concerning sexual behaviour  ☐ the sexual abuse/concerning sexual behaviours occurred within my family (eg. Relatives)

I participated in
Assessment ☐ completed  ☐ did not complete  
Treatment ☐ completed  ☐ did not complete

Please rate your Overall Satisfaction with your involvement at Thrive Child and Youth Trauma Services

Very Satisfied  ☐ Somewhat Satisfied  ☐ Neutral  ☐ Somewhat Dissatisfied  ☐ Dissatisfied  ☐ Very Dissatisfied

Please rate your Overall Satisfaction with the program you participated in at Thrive Child and Youth Trauma Services.

Very Satisfied  ☐ Somewhat Satisfied  ☐ Neutral  ☐ Somewhat Dissatisfied  ☐ Dissatisfied  ☐ Very Dissatisfied

Please rate your Overall Satisfaction with the services you received from the staff at Thrive Child and Youth Trauma Services.

Very Satisfied  ☐ Somewhat Satisfied  ☐ Neutral  ☐ Somewhat Dissatisfied  ☐ Dissatisfied  ☐ Very Dissatisfied

It is important to have specialized services like Thrive to help children and youth.

What did you like most about your counselling?  What would you change about your counselling?

Thank you for taking the time to let us know about your experiences here. Together we can make a difference for children, youth and their families!

Further reproduction of feedback forms is prohibited without permission from Thrive Child and Youth Trauma Services
sexual abuse/concerning sexual behaviours that occurred within my family (eg. Relatives)
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<table>
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<tbody>
<tr>
<td>13. My counsellor kept my personal information safe</td>
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<td>14. My counsellor's comments were fair</td>
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<td>15. My counsellor was good at their job</td>
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<td>16. Most of my treatment goals were met</td>
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<td>17. Daily activities are easier for me</td>
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<td>18. I am having an easier time coping with my feelings</td>
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<td>19. I am having an easier time managing my behaviours.</td>
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<td>20. Relationships in my life are better than before.</td>
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<td>21. Counselling helped to make my life better.</td>
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<td>22. I was supported to get help from other places (Please leave blank if not applicable)</td>
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**What did you like most about your counselling?**

**What would you change about your counselling?**

Thank you for taking the time to let us know about your experiences here. Together we can make a difference for children, youth and their families!
Please place completed form in this envelope.
Please seal envelope.
This envelope will go to the Administrative Assistant who will add your responses into a summary report.
Hamilton Service Area Feedback Form Questions | Results (N=8)
--- | ---
I waited a reasonable amount of time to get help | 4.0
My treatment was well planned | 3.7
I was involved in planning my treatment | 3.4
Most of my treatment goals were met | 3.9
Daily activities are easier for me | 3.3
I am having an easier time coping with my feelings | 3.7
I am having an easier time managing my behaviours | 3.5
I was support to get help from other places | 3.3

Note: 5= Strongly Agree, 4=Agree, 3=Neither Agree/Disagree, 2=Disagree, 1=Strongly Disagree

What have we done with the new information?
- Community Reports
- Board of Directors Reports
- Annual Summary Report for Clinicians
- Comparison, Confirming other data points
## Lessons Learned

<table>
<thead>
<tr>
<th>Successful take-aways</th>
<th>Thinking about for next time/going forward</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Engaging families</td>
<td>– Engaging youth better</td>
</tr>
<tr>
<td>✓ Knowing our community</td>
<td>– Better support for manual roll out (i.e. training)</td>
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<tr>
<td>✓ Including diverse perspectives</td>
<td>– Align implementation with youth and family engagement training and supports</td>
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<tr>
<td>✓ Recognizing agency autonomy</td>
<td>– Process for periodic check-in/follow-up</td>
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<td>✓ Partnerships</td>
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<td>✓ Timing</td>
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<td>✓ Shared vision at the service area level</td>
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<tr>
<td>✓ Utilizing a process that was values-driven</td>
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</tbody>
</table>
Children’s voices – the next frontier?

- How do we consistently and meaningfully engage younger children?
- Need to be creative!
  - e.g. Lynwood Charlton Centre ran a “Speakers’ Corner”
Acknowledgements

- Youth and families who contributed to this process
- All our Hamilton Core Service Providers
- Our community partners
- Children’s Mental Health Ontario for inviting us to share our story!
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Al Cudmore, Implementation Specialist
Alan.Cudmore@camh.ca
Agenda

1. **Background & Context** – Catherine
2. **Service Area & Lead Agency** – Catherine
3. **System Level & Research** – Laura
4. **Engaging Youth & Families** – Louise
5. **Core Service Provider Implementation** – Nancy
6. **System & Research Implication Workshop** – facilitated by Al Cudmore (CAMH)