A Comprehensive Characterization of the Extensive Needs Service Pilot Program Participants in Ontario

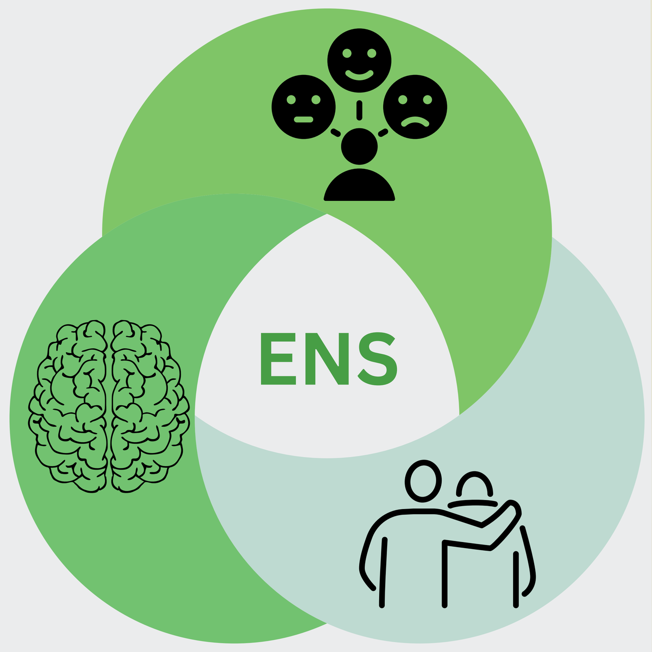
Olaseni, B., Rombos, V., Salami, Z., Ferguson, G., Penner, M.

Background

The Extensive Needs Service was created to address the unmet needs of many children and youth by providing wrap-around care

<u>Intersecting Needs</u>

Developmental
Social
Mental
Physical



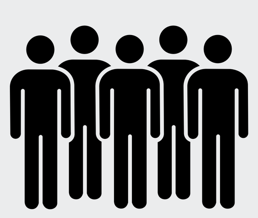
Objectives

<u>Describe the:</u>

- **Demographics** of ENS families
- **Baseline outcome measures** of the ENS families

Methods

<u>**Participants:**</u>
22 children and youths **(12 males, 10 females)** from Holland Bloorview.



<u>**Baseline measures:**</u> Demographics, Brief Family Distress Scale (BFDS), Pediatric Global Health-7 (PGH-7), and Behaviour Assessment System for Children-3 (BASC-3).

<u>**Analyses:**</u>
Demographic trends (age groups, race, income) described using **proportions**.

Median to describe BFDS and PGH-7: Quality of Life (QoL) and mental health.

Mean with standard deviation for BASC-3 T-scores for externalizing behaviours.

Families in the ENS program often have **multiple complex diagnoses**, primarily come from **low-income backgrounds**, and experience **significant family distress** and **poor mental health**.

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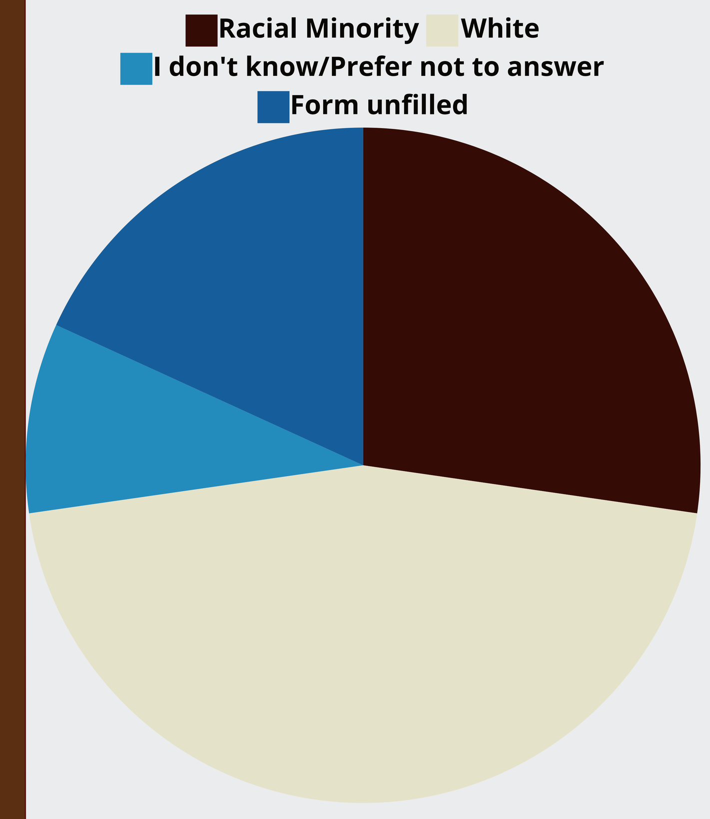
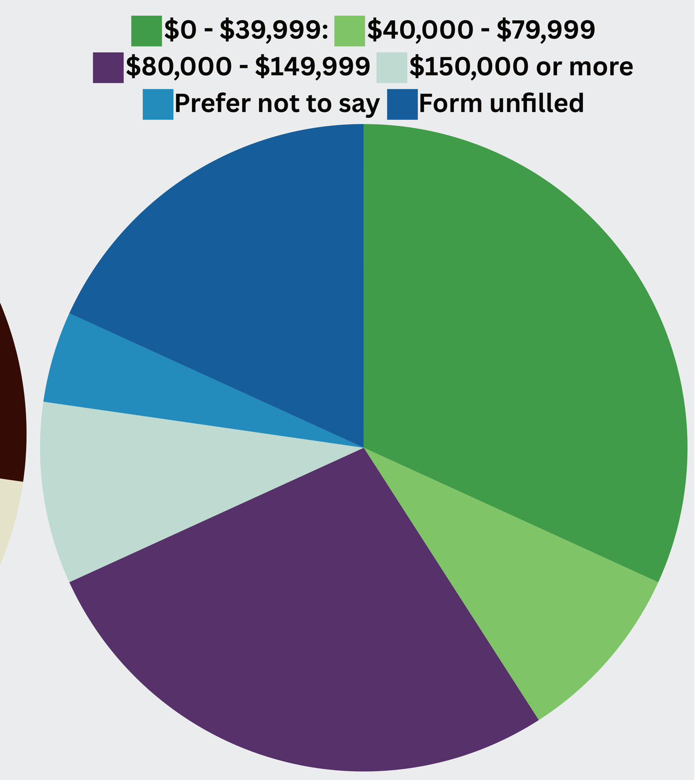
Results

31.6% of participants were racial minorities



Majority of participants fall in the low family income bracket



Half of the participants were aged 6-11

<u>**BFDS**</u>	<u>**PGH-7**</u>	<u>**BASC Externalizing**</u>
Median BFDS score was **5/10** ("Things are very stressful, but we are getting by with a lot of effort")	Mental health: **2/5 (fair)** QoL: **3/5 (good)**	68.5 (SD=14.9) indicating **at risk levels** (n=19)

Conclusion/Next Steps

<u>**Baseline data reveals:**</u>

- Significant family distress and
- Poor mental health among ENS participants

These insights will help refine the ENS program by improving **intake processes** and **tailored program delivery** to better address the needs of youth with complex issues.

Relevance

- By categorizing and describing ENS families, the program can better meet **distinct individual needs**.
- This will also help in **targeting advocacy** for these populations whose needs are being left unmet by the system, ultimately benefiting Holland Bloorview clients and families.

Early Identification of Autism Spectrum Disorder Using XGBoost and Convolutional Neural Network with Magnetic Resonance Imaging Data

Elliott Wong[1,2], Evdokia Anagnostou[1,2], Jacob Ellegood[2]
[1] Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada; [2] Autism Research Center, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada

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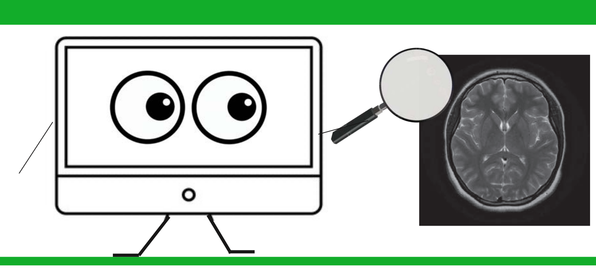
autism RESEARCH CENTRE

BACKGROUND

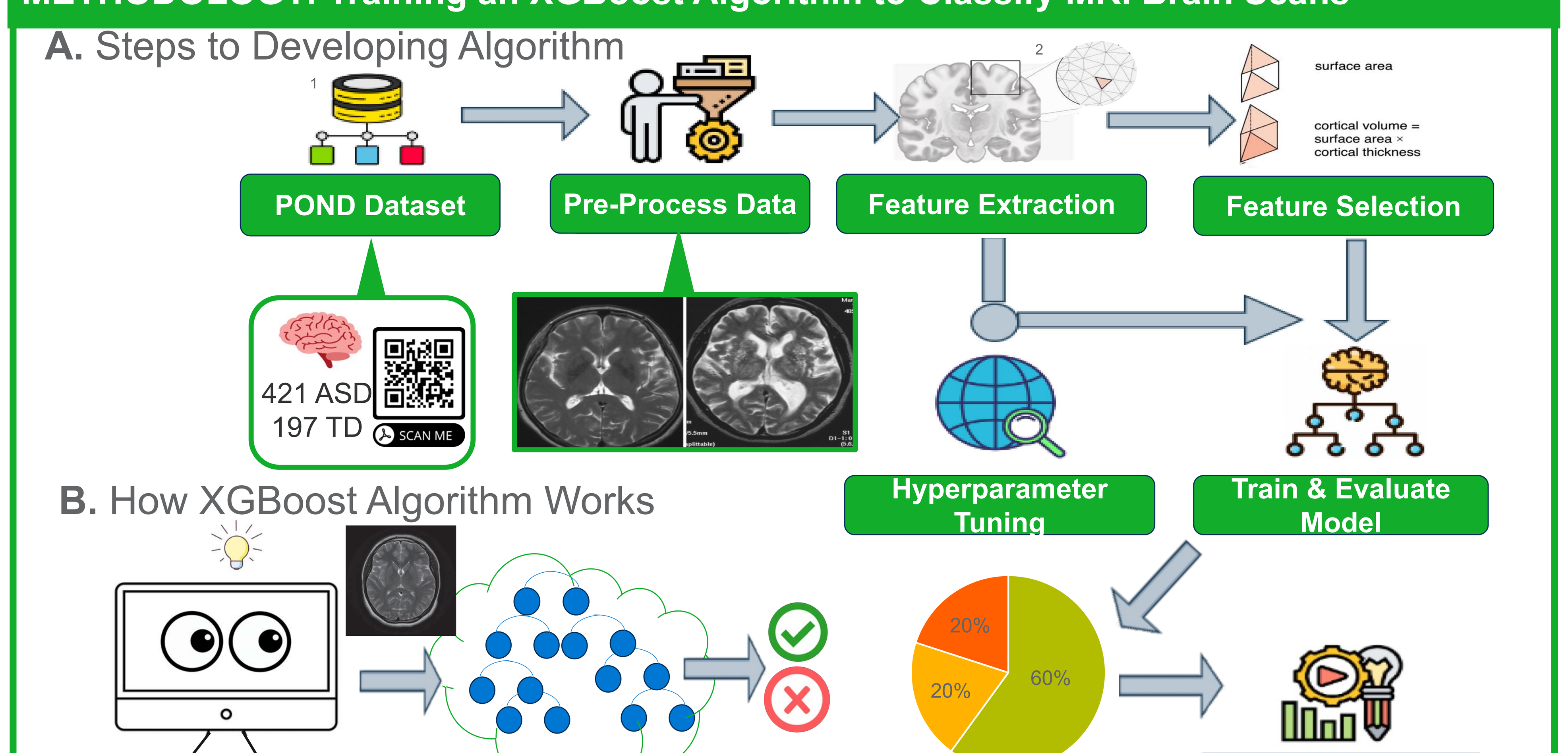
- Autism spectrum disorder (ASD) is a heterogeneous, neurodevelopmental condition that impact communication, social abilities and behaviours
- **One in 50 children** live with autism spectrum disorder (ASD) yet wait-times for diagnosis is **over 1-3 years**
- **Magnetic resonance imaging (MRI)** can detect differences in brain structure, connections and activity in children with ASD ages 2-5 compared to typically developing (TD) children
- **Machine learning models** (i.e. **XGBoost**) can analyze images (i.e. MRI) and identify patterns from complex data to make informed predictions
- Few studies have developed models to predict ASD in children ages 2-5 using MRI

RESEARCH QUESTION

How effectively can machine learning models (i.e. **XGBoost**) **classify** ASD in children ages 2-5 using MRI brain scans?



METHODOLOGY: Training an XGBoost Algorithm to Classify MRI Brain Scans



1. **Uddin MJ**, **Ahamad MM**, **Sarker PK**, **Aktar S**, **Alotaibi N**, **Alyami SA, Kabir MA, Moni MA**. An integrated statistical and clinically applicable machine learning framework for the detection of autism spectrum disorder. Computers. 2023 Apr 30;12(5):92.
2. **Pretzsch CM, Ecker C.** Structural neuroimaging phenotypes and associated molecular and genomic underpinnings in autism: a review. Front Neurosci. 2023 Jun 30;17:1172779. doi: 10.3389/fnins.2023.1172779.

Early differences in brain structure in ASD may be informative markers for guiding diagnosis but alone are not sufficient

SCAN ME

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XGBOOST RESULTS

75.2% accuracy
in predicting ASD among children ages 2-5

96% sensitivity
in classifying ASD using 340 brain features (i.e. volume, thickness, area)

Fig 1. Area Under the Curve (AUC)

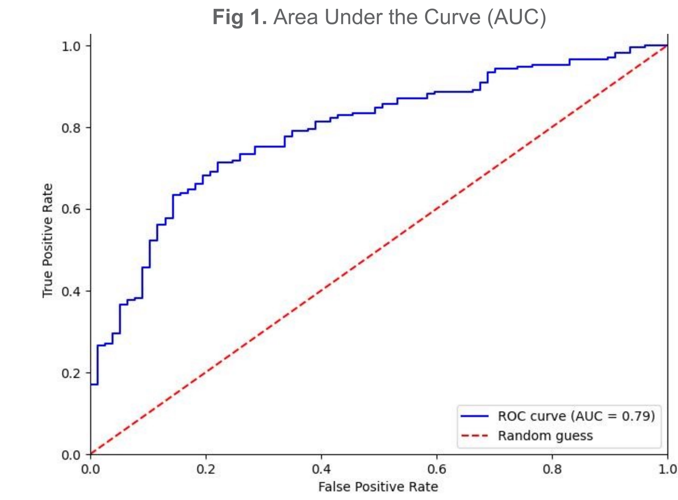


Fig 2. Confusion Matrix

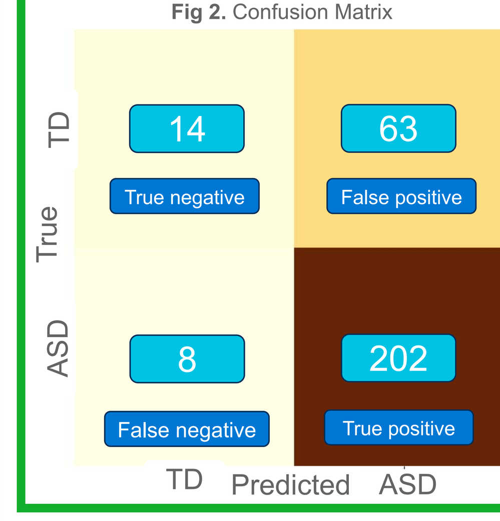
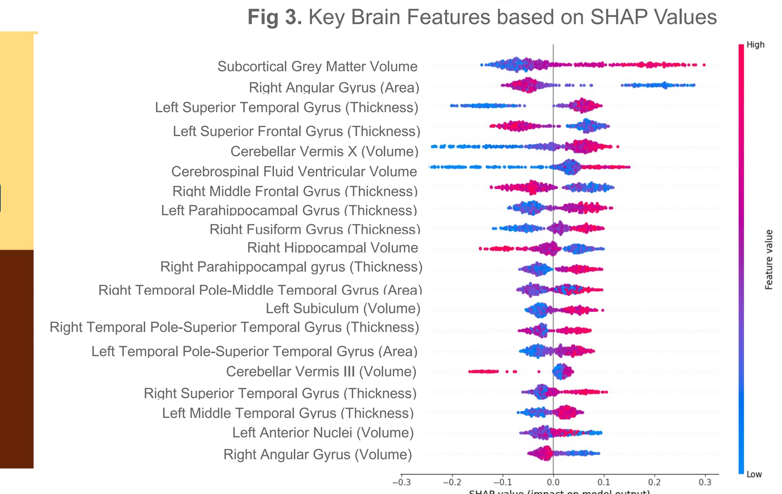


Fig 3. Key Brain Features based on SHAP Values



DISCUSSION

Potential: Highlights utility of developing age-specific machine learning models for ASD on children ages 2-5. Early MRI scans may overcome the complexity heterogeneity in ASD.

Relevance: Guide diagnosis, reduce wait-times for assessment and access to services for young children with ASD

Limitations: Few subjects, need to assess generalizability

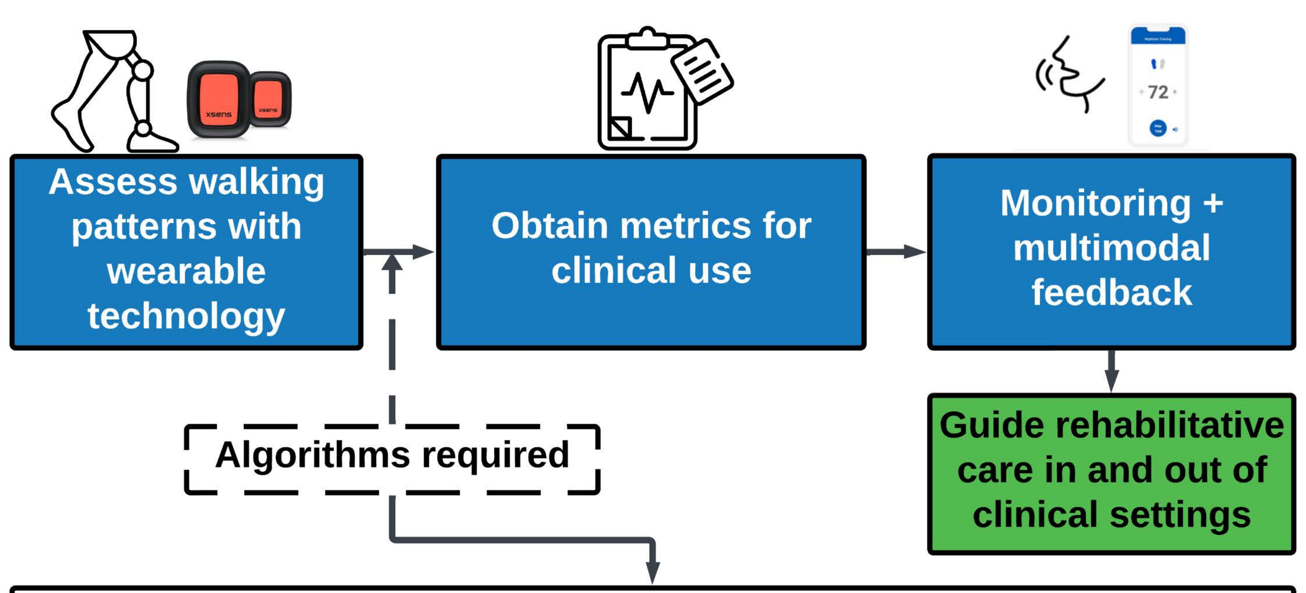
Next Steps: (A) Evaluate model performance in distinguishing anxiety, OCD and ADHD. (B) Compare performance with **convolutional neural network**

Development and Validation of Machine Learning Algorithms to Evaluate Overall Walking Patterns of Lower Limb Prosthetic Users using Inertial Sensors.

Kuepper E.[1,2], Ng G.[1,3], Andrysek J.[1,3]

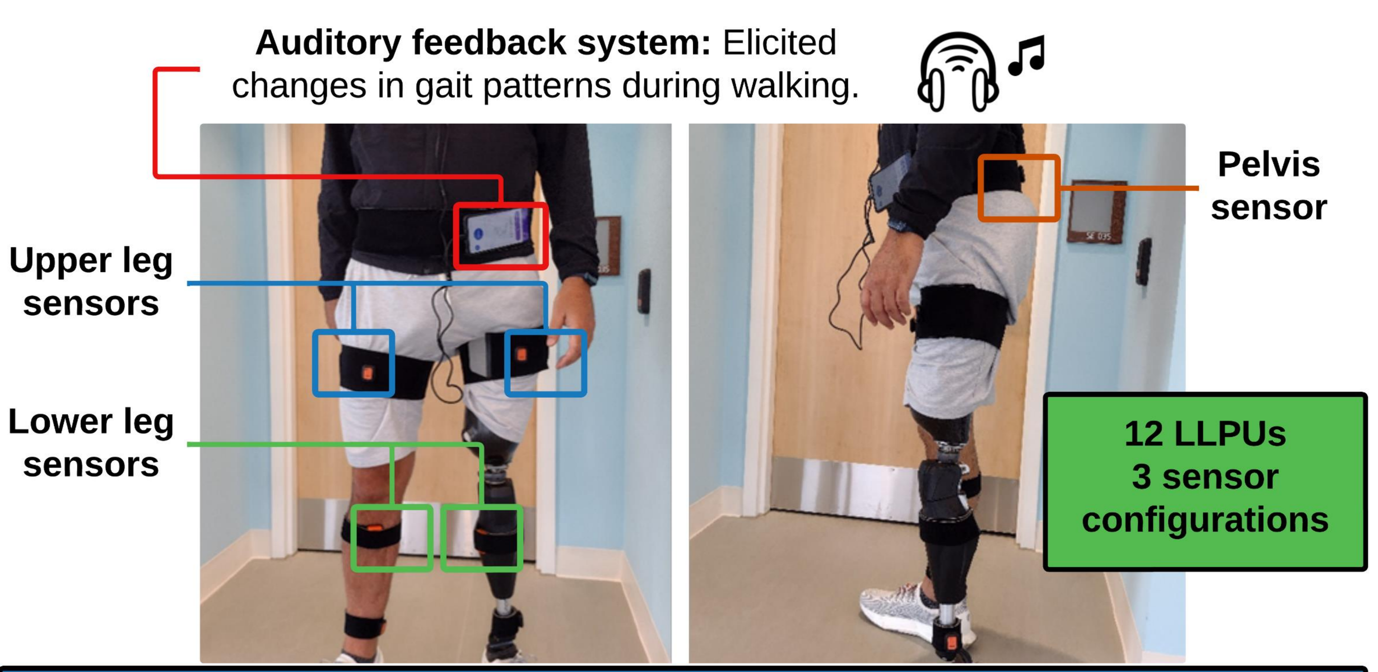
1. Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital
2. Integrated Biomedical Engineering and Health Sciences, McMaster University
3. Institute of Biomedical Engineering, University of Toronto

Background & Objective

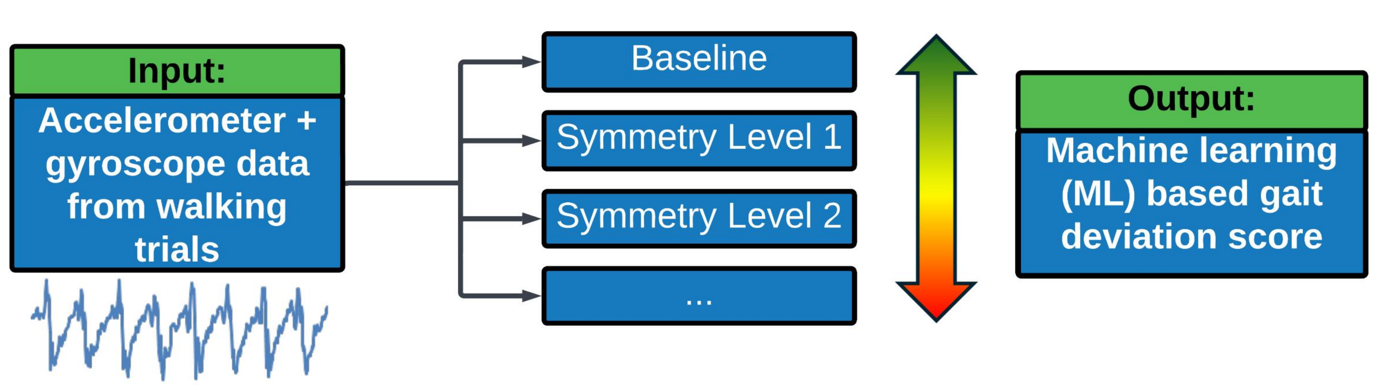


Objective: Validate a machine learning (ML) algorithm to **assess changes in walking patterns** corresponding to **clinically relevant gait parameters** for lower limb prosthetic users (LLPUs).

Methods



Hidden Markov model (HMM), self-organizing map (SOM), and dynamic time warping (DTW) were implemented to **detect changes** in stance time symmetry **from baseline**.



Combining Simple Wearable Technology With Machine Learning to Assess Walking Patterns in Lower Limb Prosthetic Users.

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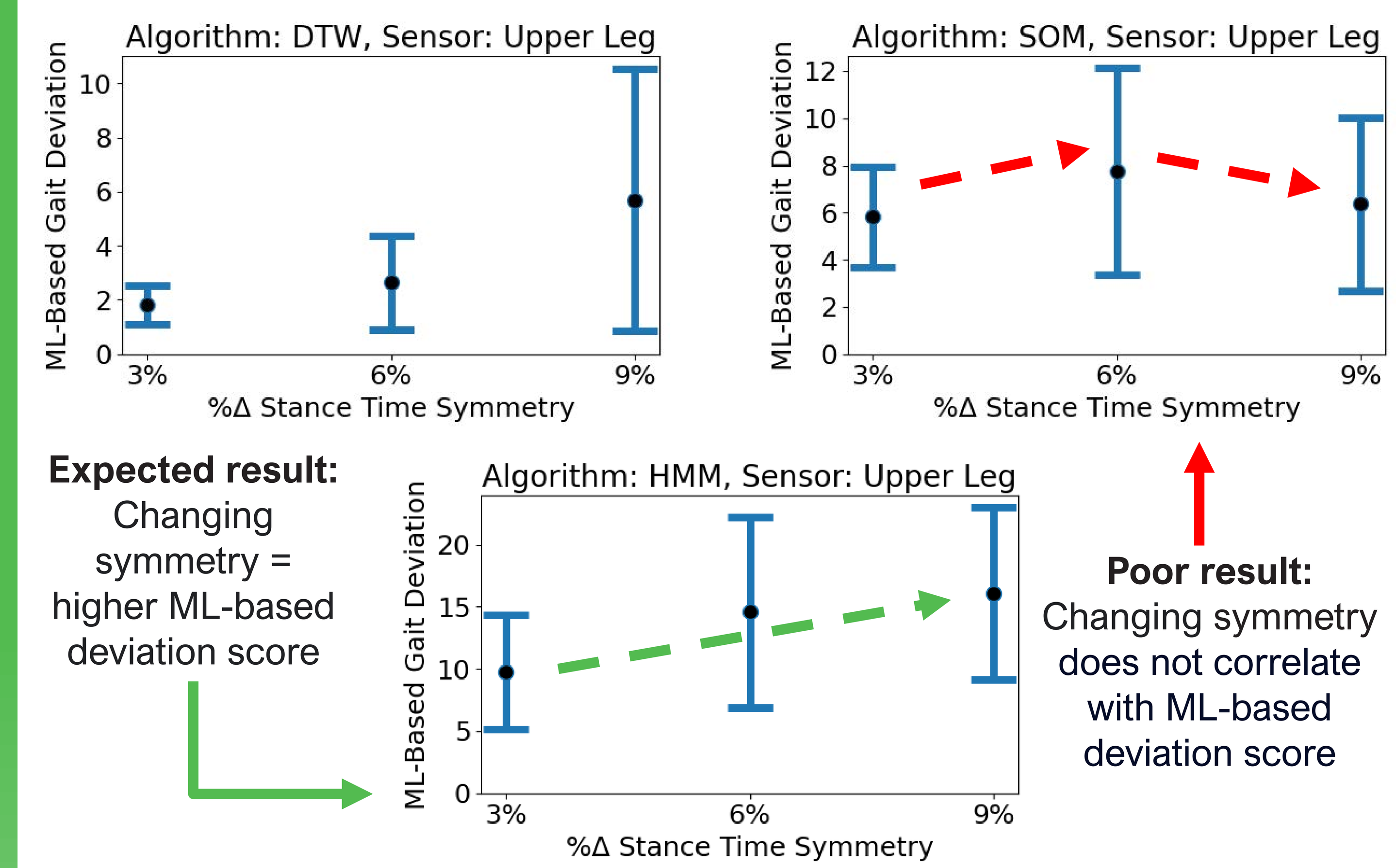
Holland Bloorview
Kids Rehabilitation Hospital

Results

Example – Mean + 95CI of ML-based gait deviation scores across symmetry levels



Effect Size – Standardized Response Mean (SRM)

Low Moderate High responsiveness

Sensor Location	Pelvis			Upper leg			Lower leg		
Symmetry Change	3%	6%	9%	3%	6%	9%	3%	6%	9%
DTW	0.05	0.15	0.41	0.33	0.66	0.61	0.45	1.76	1.46
SOM	0.24	0.04	0.02	0.18	0.05	0.07	0.3	0.82	1.04
HMM	0.62	0.78	0.85	0.69	0.87	1.82	0.77	0.58	0.63

- **HMM** → moderate-high responsiveness for all sensor locations and gait symmetry levels.
- **Lower leg sensor location** → highest responsiveness across all algorithms.

Conclusions

✓ ML algorithms trained on inertial sensor data can be responsive to changes in stance time symmetry.

Next steps:

❑ Assess responsiveness of algorithms to changes in other gait parameters (ex. step length).

Impact

Wearable systems can **offer cost-effective, portable, and user-friendly gait monitoring**. When integrated with reliable gait evaluation models, these systems could:

1. Provide **real-time feedback** without a clinician present.
2. Monitor changes in and out of the clinic to **inform clinical decision making and rehabilitation goals.**

Creating and Testing a Brian-Controlled Musical Instrument for Therapy in Children with Cerebral Palsy

Jirreh. H, Tou. J, Chau. T

Background

Children with cerebral palsy (CP) often experience variations in attention span, hindering other cognitive development areas [1].

Neurologic Music Therapy (NMT)

Effective in enhancing attention and concentration in children with neurological disorders [2].

Brain-Computer Interface (BCI)

Electroencephalogram (EEG)-BCI can improve accessibility to NMT for children with CP [3].

Objective

To design and evaluate an EEG-BCI-enabled music instrument for neurologic music therapy to improve attention in children with CP.

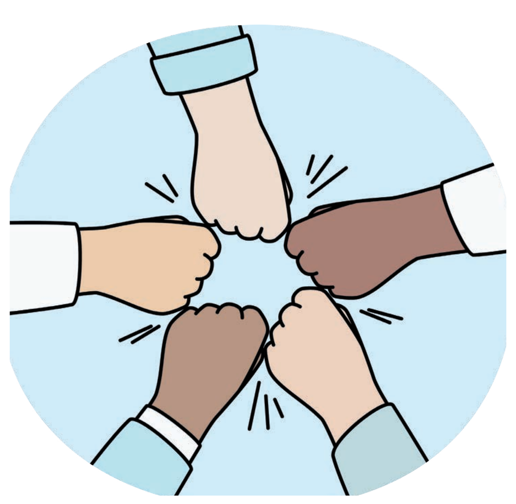
Methods

System Configuration Involved

1 The BCI R-Net Headset
Served as the interface for capturing brain activity signals.

2 The Mindset Application
Facilitated the connection between BCI and the sound beam through a relay box.

3 The Sound Beam
Generated the desired musical output based on the user's mental commands.



Protocol and Goals Development

Collaborated with an interdisciplinary team of other **researchers, clinicians, and music therapists** to inform protocol development and therapeutic goals.

Integrating BCI technology into music therapy is an innovative and enjoyable way to enhance therapeutic outcomes for children with CP

Holland Bloorview Kids Rehabilitation Hospital

Bloorview Research Institute

Results

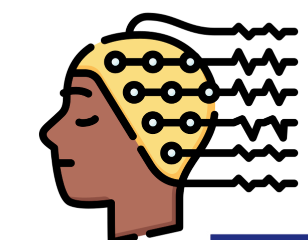
System testing demonstrated that BCI integration facilitated user control of the sound beam, producing a musical output through mental commands.

Next Steps

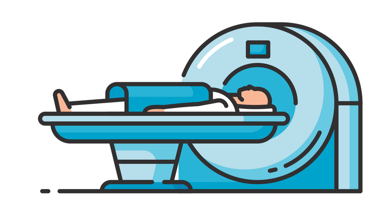
5 children with CP will be recruited to participate in **8 weeks of BCI-NMT sessions**. Outcomes will be measured using changes in Test of Everyday Attention for Children 2 (Tea-Ch2) results, EEG recordings, and neuroimaging.

TEA-Ch2 Attention Tests

EEG Recordings



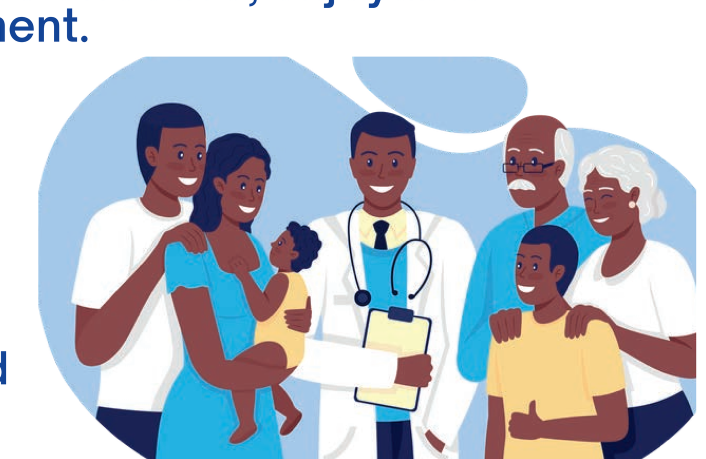
Neuroimaging



SCAN FOR STUDY INFORMATION

Relavance

- Reinforces Holland Bloorview's commitment to holistic, family-centered care.
- Ensures effective, enjoyable treatment.
- Aims to enhance the quality of life for children with CP and their families.



References

[1] Yang, S. et al. (2022). https://doi.org/10.3389/fneur.2022.852277
[2] Santonja-Medina, C. S. et al. (2022). https://doi.org/10.3389/fneur.2022.795533
[3] Karlsson, P. et al. (2022). https://doi.org/10.1007/978-981-16-5324-7_2

Understanding recommendations to policy, practice, and removal of barriers to enhance the experiences of youth with disabilities with multiple minoritized identities

Jaden Lo[1,2], Janice Phonepraseuth[1], Lily Cao[1], Sally Lindsay[1,3]
1.Bloorview Research Institute, 2.McMaster University, 3.University of Toronto

Background and Rationale

Youth living with disabilities experience varying forms of discrimination, which can often be exacerbated by prejudices against their marginalized groups.

Disability	Race	Gender	Ethnicity	Experience

It is **crucial** to consider the perspectives of youth living with disabilities.

Research Question

What shifts to policy and practice may be needed, and barriers removed to ensure that youth with disabilities thrive in all their diversity?

Design and Methods

Ages 22-29 years (mean age 25.4)

Nine transcripts from interviews with youth with disabilities, identifying as belonging to a racial, ethnic and/or gender minority group.

1) Initial screening of transcripts reviewed by three researchers.

2) Collaboratively established coding manual with TRAIL Team.

3) Independently conducted coding using standardized coding manual.

Youth with disabilities belonging to minoritized groups are seeking more accessibility to inclusive spaces and continued advocacy for disability awareness.

SCAN ME

Thank you to the Ward Family for funding the summer student program.
This research was funded by SSHRC and the Kimel Family fund.

Results and Key Themes

1. A need to increase accessibility to accommodations.
2. Request for more inclusive spaces, physical or virtual.
3. Encouraging advocacy among youth.
4. Promoting disability awareness within communities.
5. Appreciating the intersectionality of individuals.

*"...so that people can be **involved**, people can be **engaged**, and people **can share their opinions and contribute** to the creation delivery of services and the ongoing conversation of disability. It's never going to be, "oh yes, now we are done"." -P04*

Social Model of Disability and Principles of Disability Justice were among the models recommended by participants.

1.

Relevance to Holland Bloorview Clients and Families

By highlighting and listening to lived experiences, recommendations and expected challenges can be catered to clients in a manner that sheds light on pertinent issues.

Conclusions and Next Steps

Continued research must focus on the implementation of:

Client-centered discussions → Relevant Recommendations ← Client-informed initiatives

Next steps should include investigating the feasibility of implementing recommendations and continued discussing with clients.

1. Generated with NVivo

Project: Deep Learning (DL) Enabled EEG Artifact Removal Algorithms for Real-World BCI Applications

Wan. J, Floreani. E, and Chau. T

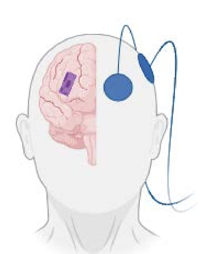
Background

Typical BCI workflow

Signal Acquisition | Feature Extraction | Device Interface

Accuracy of the BCI task is affected by the amount of noise in the EEG signal

Objective



Does EEG noise removal using DL techniques improve performance of real world BCI tasks?

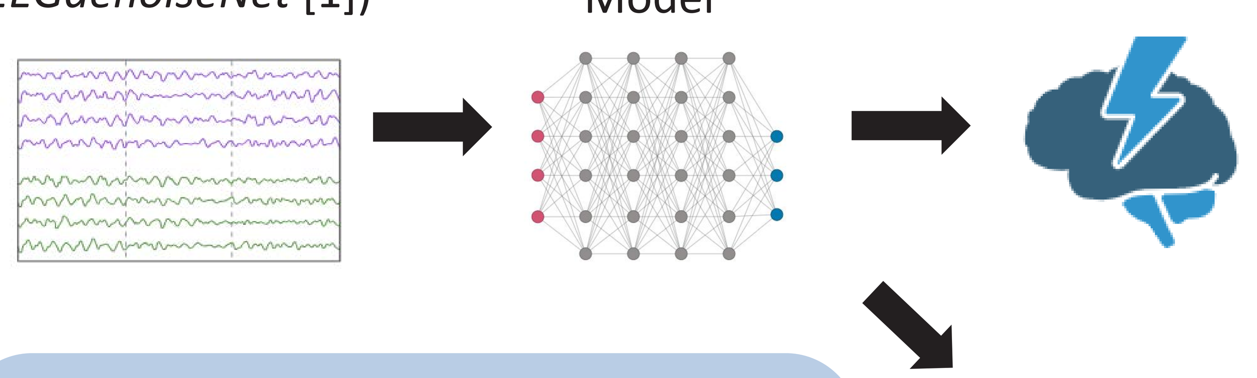
Methods

DL Pipeline for BCI Validation

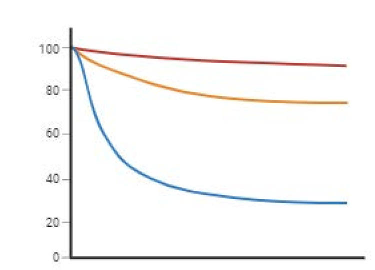
Open-access dataset (*EEGdenoiseNet* [1])

Deep Learning Model

BCI Task Validation [2]



Model Evaluation



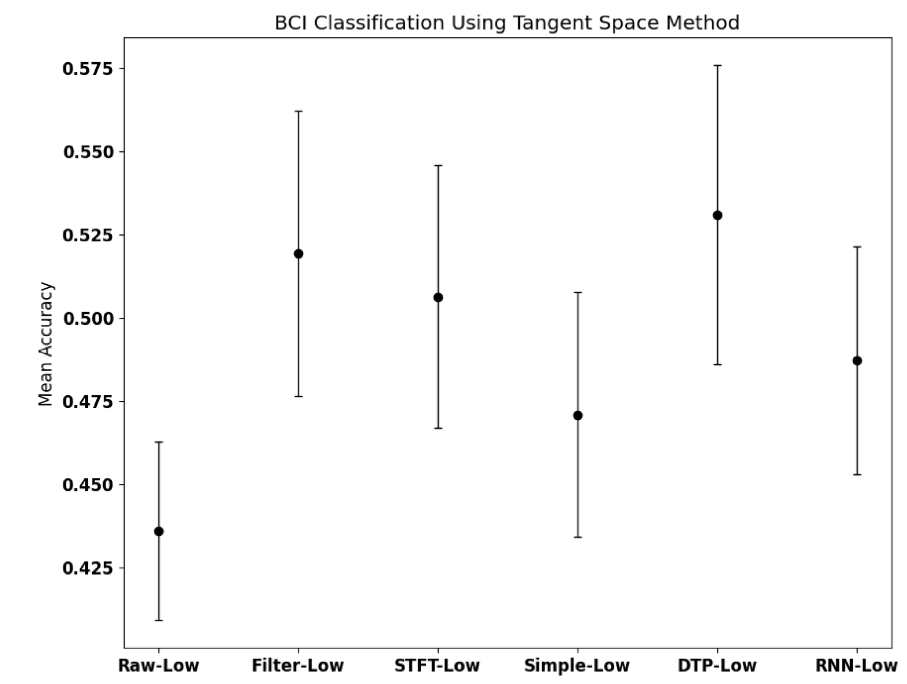
Baseline and state-of-the-art models from literature, as well as a novel Short-time Fourier Transform based CNN model were compared.

Removing Noise From Brain Signals with AI to Improve Brain-Computer Interface (BCI) Tasks

Holland Bloorview
Kids Rehabilitation Hospital

UNIVERSITY OF TORONTO

Results



Model	Accuracy	Model Size
SimpleCNN	0.47 ± 0.04	10.5M
RNN	0.49 ± 0.03	788k
DTPNet	0.53 ± 0.04	40M
Our model (STFT)	0.51 ± 0.04	16M

Conclusion

- Overall, DL models improved the performance of the classification task.
- Results from DL models were comparable with bandpass filtering, a traditional noise removal technique.
- Our novel CNN is the second-best performing model amongst all the DL algorithms.

Next Steps

1. Evaluate level of noise in validation dataset
2. Further analyze properties of BCI data
3. Experiment with other BCI datasets

Relevance

Development of novel EEG artifact removal techniques will enhance BCI usability in real-world environments, extending benefits children with severe motor disabilities.

References: [1] Zhang, H., Zhao, M., Wei, C., Mantini, D., Li, Z., and Liu, Q. (2021b). EEGdenoiseNet: a benchmark dataset for deep learning solutions of EEG denoising. *J. Neural Eng*. 18:056057. doi: 10.1088/1741-2552/ac2bf8
[2] Goldberger, A., Amaral, L., Glass, L., Hausdorff, J., Ivanov, P. C., Mark, R., ... & Stanley, H. E. (2000). PhysioBank, PhysioToolkit, and PhysioNet: Components of a new research resource for complex physiologic signals. Circulation [Online]. 101 (23), pp. e215–e220.

Parental Concerns on Patience and Behaviour Management for Children with Disabilities During COVID-19

Aryeetey J., Lamptey, D.

Background

Physical, emotional, cognitive, and behavioural disabilities require unique care and support systems, and adequate access to these services is essential to the child's health.

The sudden COVID-19 Lockdowns shut down many health and childcare services globally, disrupting access to many essential services

However, the closure of these services had a distinct impact on families of children with disabilities

Research Question

Is there a relationship between disability and parental concerns regarding having patience with and/or managing a child's behaviour/emotions during the COVID-19 pandemic?

Methods

Data Collection

Crowdsource File: Impacts of COVID-19 on Canadians - Parenting During the Pandemic

- Collected by Statistics Canada
- Participants included parents of children aged 0-14 years throughout Canada
- **Key Variables:**
- Familial Demographic factors: Child has disability, Indigenous identity, visible minority status, and employment status
- Dependent: Concern for family - Having less patience with child, Concern for family - Managing child's behaviour/emotions

16.9% of all respondents reported having a child between 0-14 with a disability

Data Analysis

- A binomial regression model was used to assess how disability status is associated with these concerns
- Behaviour Concerns measured as 'No Concerns' (N=2405) vs. 'Some Concern' (N=29772), Patience (N=4402 – No Concern, N=27792 – Some Concern)

Controlled for other sociodemographic factors

Socio-economic characteristics + Province of Residence

Families with children aged 0-14 with disabilities experience increased concerns about how they will manage their child's behaviour and emotions during the COVID-19 pandemic

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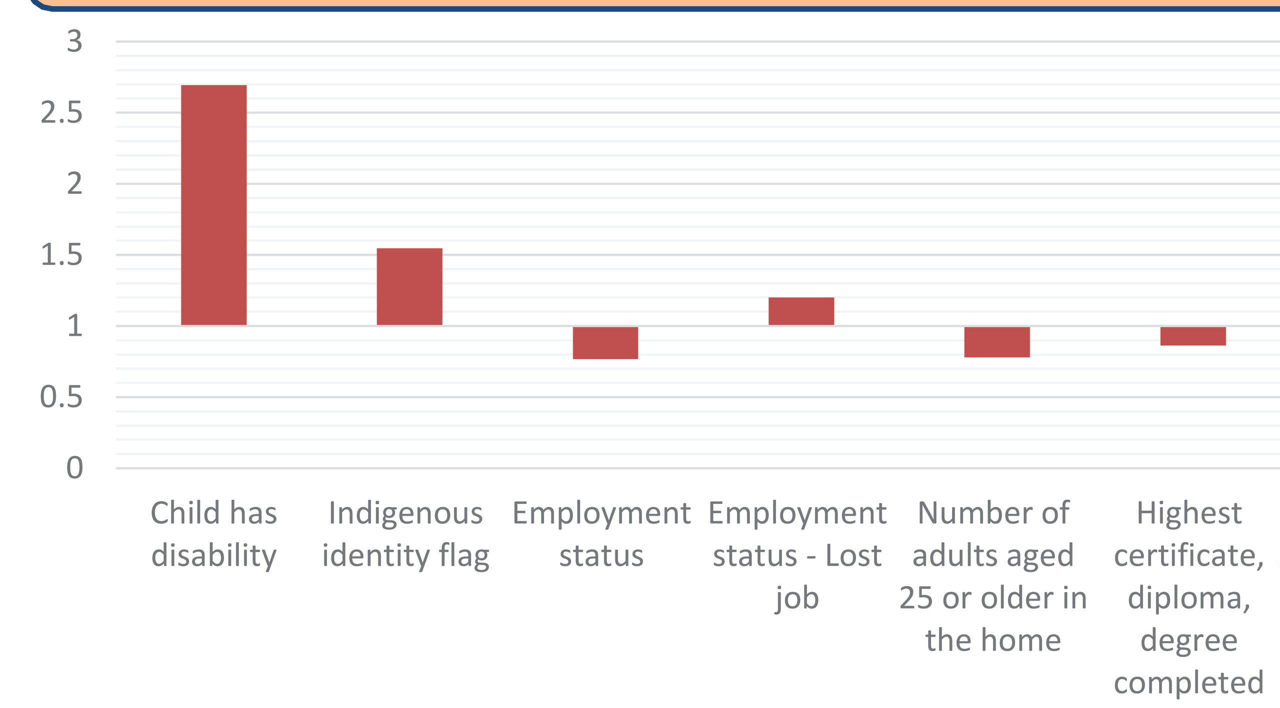
Results

Disability significantly predicted increased parental concerns about managing children's behaviour.

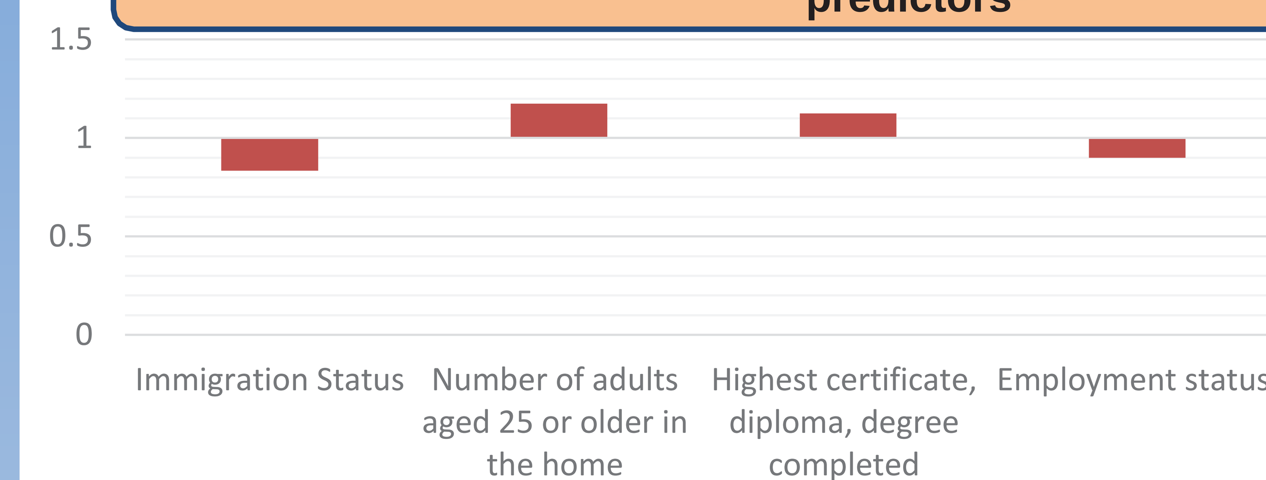
Families with all family members working from home also experienced increased concern

Figure 1: Concern for family - Managing child's behaviour/emotions vs Demographic and Socioeconomic Indicators[1]



Y=1 represents child without disability, non-Indigenous, all family members employed from home, only 1 adult in the home, and parent did not attend university

Figure 2: Concern for family - Having less patience with child significant predictors[1]



Y=1 represents non-Immigrant or non-permanent resident, only 1 adult in the home, parent did not attend university, and all family members employed from home

[1]Controlled for parental demographic factors: child with disability, visual minority status, Indigenous identity, education level, immigration status, employment status, province of residence, and number of adults in the home

Disability significantly predicts behaviour management concerns (X^2= 2.69, $p < 0.05$). However, disability is not a significant predictor of patience concerns (X^2 = 1.085, $p > 0.05$) after demographic adjustments

Conclusion

Families of children with disabilities experience increased concern about managing their child's behaviour and emotions, regardless of demographic

=

Targeted support is important during global crises

Relevance to Holland Bloorview

Identifies the need for specialized mental health and behavioural support services for families with children with disabilities

Informs policymakers on how the COVID-19 shutdown affected families of children with disabilities

Utilizing Digital Technology to Develop a Workflow for Creating Personalized and Accessible Prosthetic Covers

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1. Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital
2. Mechanical Engineering, McMaster University
3. Institute of Biomedical Engineering, University of Toronto

BACKGROUND

Prosthetic covers aesthetically enhance prosthetics, providing individual customization to the leg

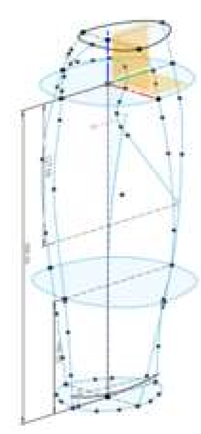
CHALLENGES FACED BY CLIENTS:

- High costs
- Chipping/Cracking
- Slow design process from external manufacturers

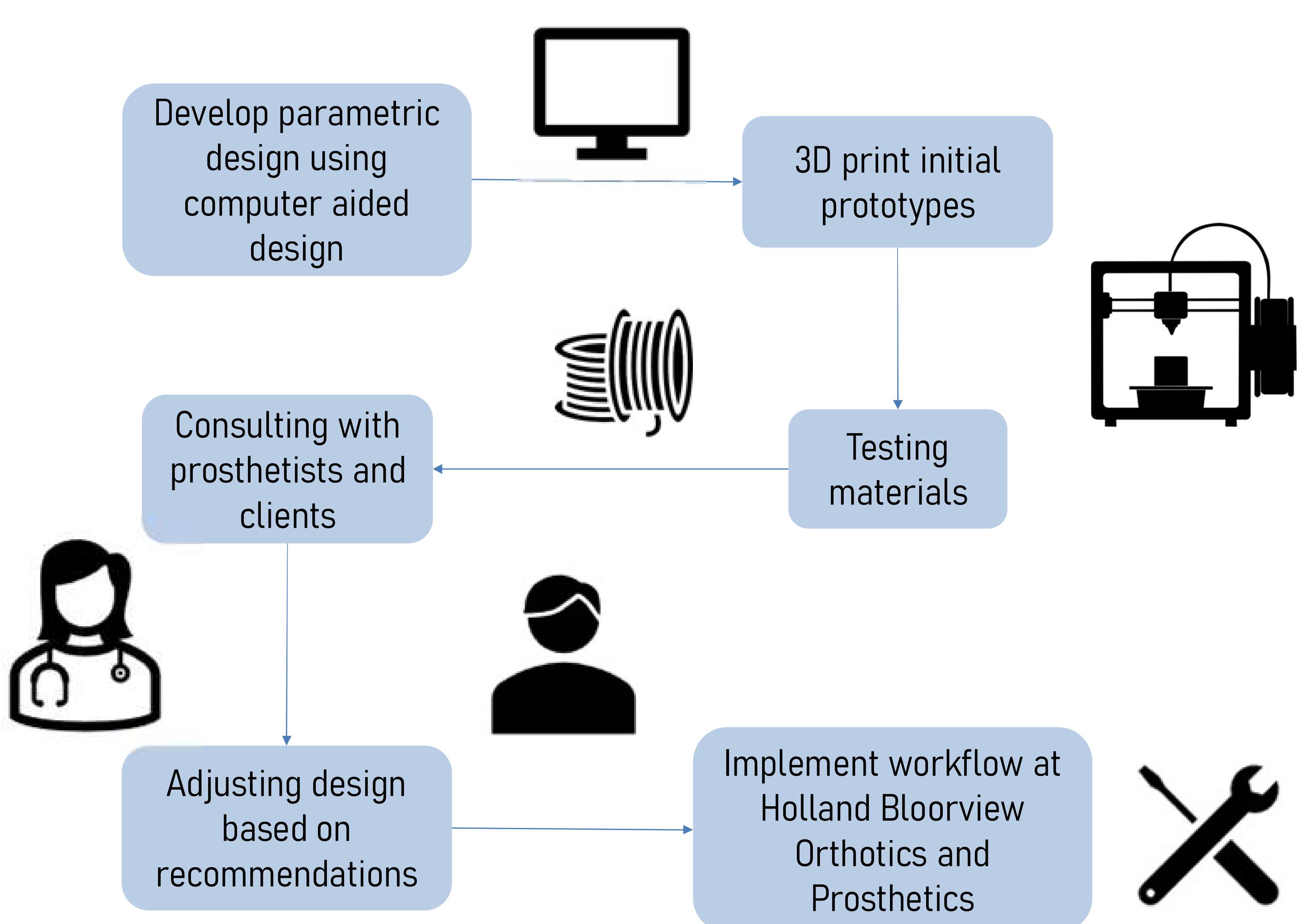
OBJECTIVE

CREATE A WORKFLOW THAT:

- Allows for design and shape personalization
- Enables prosthetists to create designs quickly
- Is cost effective in comparison to external manufacturers



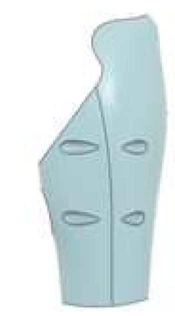
METHODS



Developing Personalized and Accessible Prosthetic Covers with Digital Technology

DESIGN CONSIDERATIONS

LEG SHAPE



Ankle shape, muscle shape and leg height must be similar

FIT

Prosthetic must fit within cover

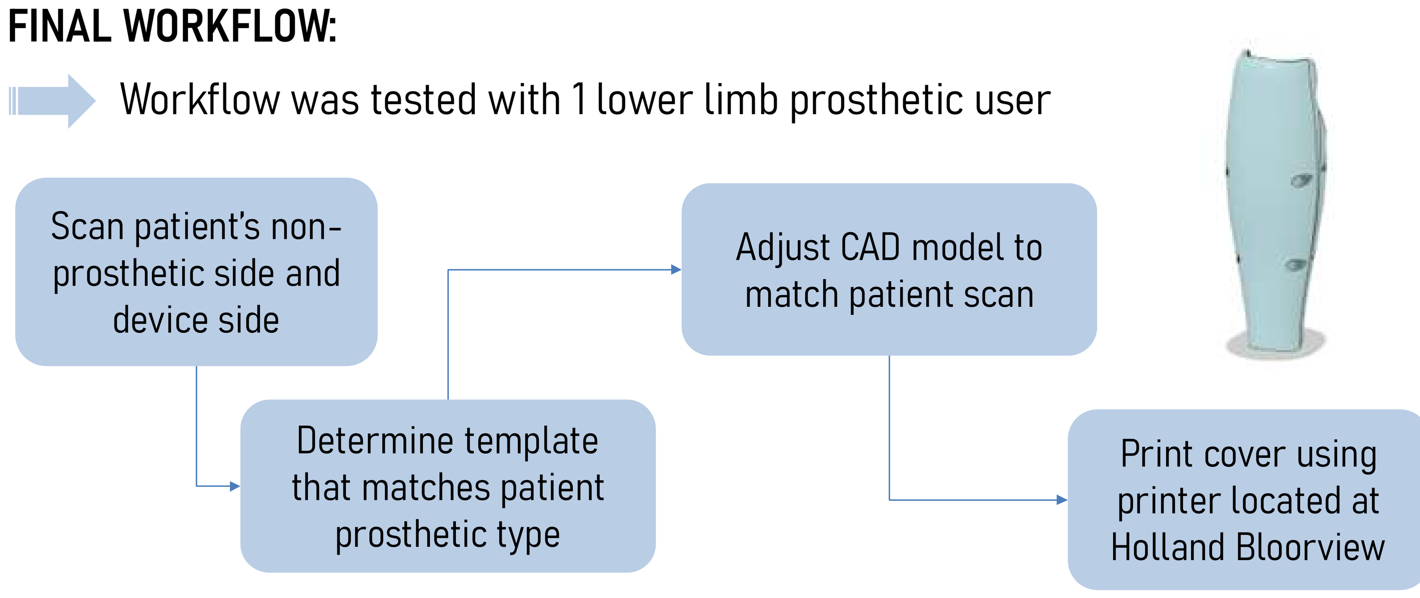
CONNECTION METHOD

Connection must be secure to prevent separation

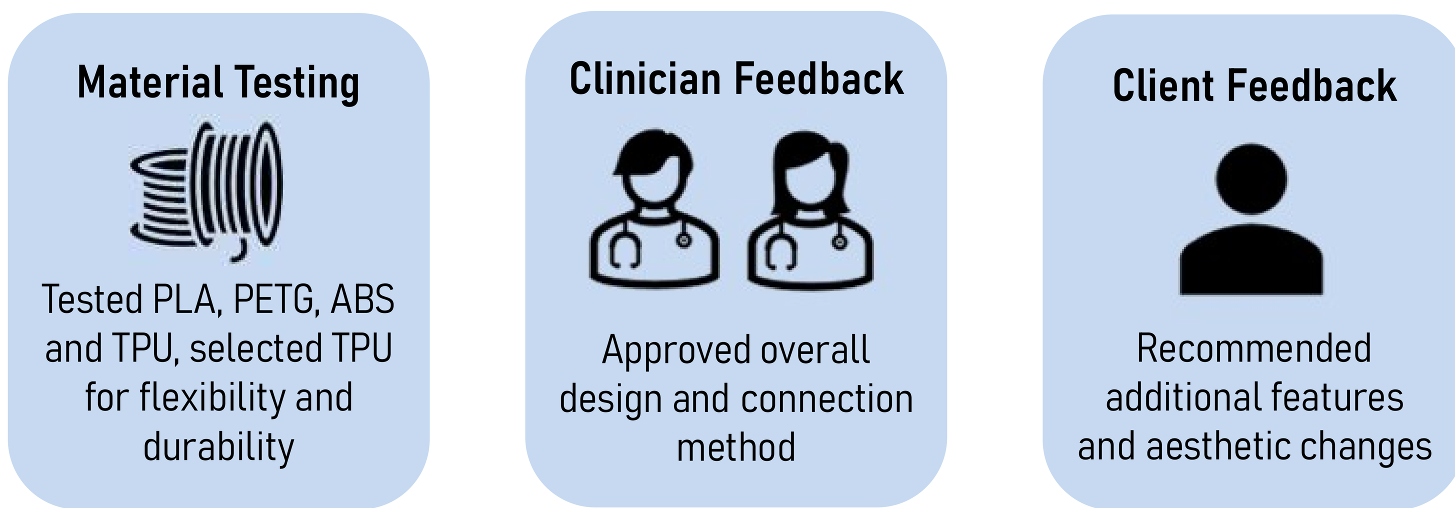
RESULTS AND DISCUSSION

FINAL WORKFLOW:

- Workflow was tested with 1 lower limb prosthetic user



TESTING AND FEEDBACK:



NEXT STEPS:

- Assess workflow compatibility with other prosthetic device types

IMPACT

By bringing this process in-house, the Holland Bloorview O+P department can:

- Provide clients with enhanced customization and personalization for their prosthetic cover
- Provide clients with an affordable alternative to external manufacturers

ACKNOWLEDGEMENTS

I would like to thank the PROPEL Lab and the Holland Bloorview Orthotics and Prosthetics Department for their support and guidance in this project.

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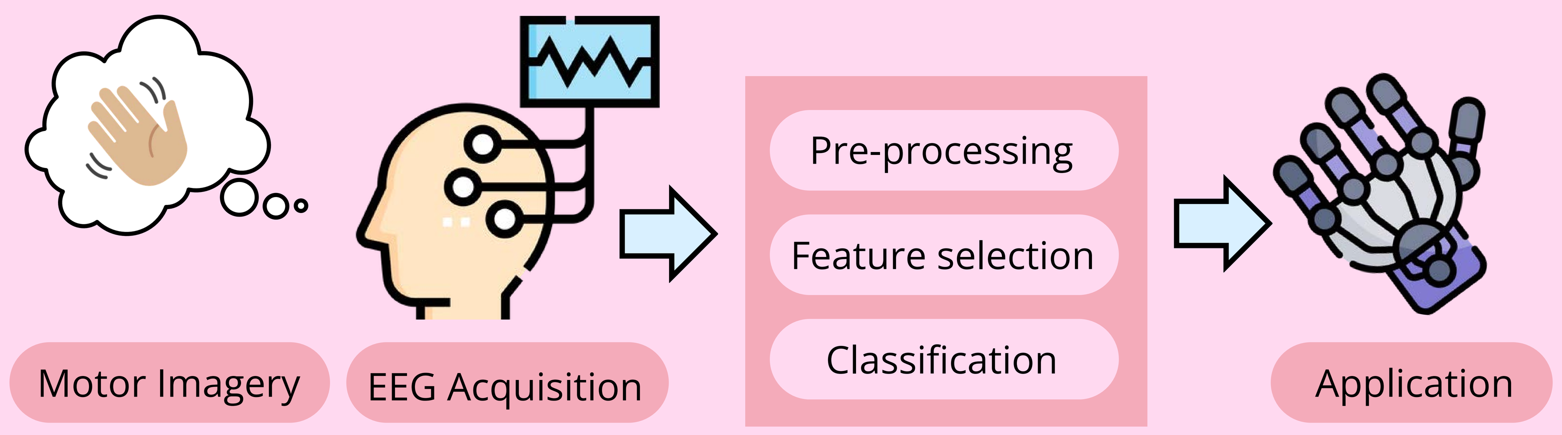
Combination of unsupervised clustering and linear classification to enhance brain-computer interface classifiers

Madeline Wong[1], Nicolas Ivanov[2], Tom Chau[2]

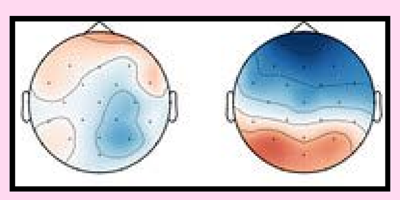
1. University of Waterloo, Department of Systems Design Engineering
2. University of Toronto, Institute of Biomedical Engineering

Background

Brain-computer interfaces (BCIs) enable people to control external devices through their neural activity by performing mental tasks



Different mental tasks produce unique patterns of electrical activity in the brain which can be classified by the BCI and used to **map thoughts to physical actions**



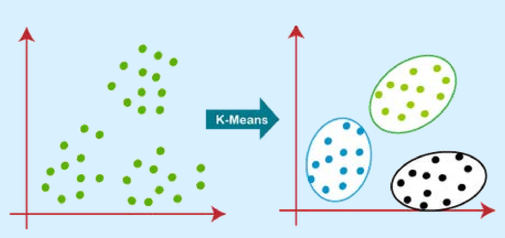
Clinical use of BCIs is limited because **task-irrelevant brain activity occludes task-relevant modulations**, impeding the BCIs ability to accurately classify the true tasks the user is performing.

Research Question

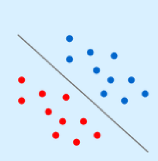
Does combining unsupervised clustering with traditional linear classifiers for BCI task decoding improve prediction accuracy?

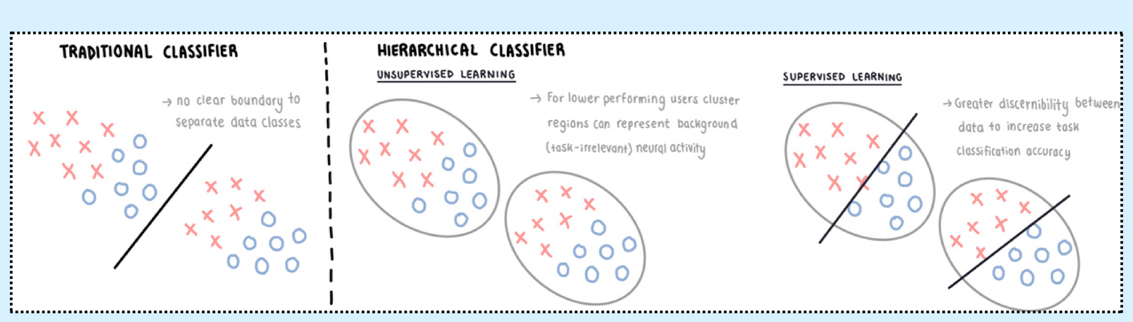
Methods

1. **K-means clustering** applied to segment each participant's data into regions of similar neural patterns



2. Within each cluster region, **linear classifier** applied to make task predictions





Improving Brain Computer Interface accessibility by combining machine learning methods.

Learn more

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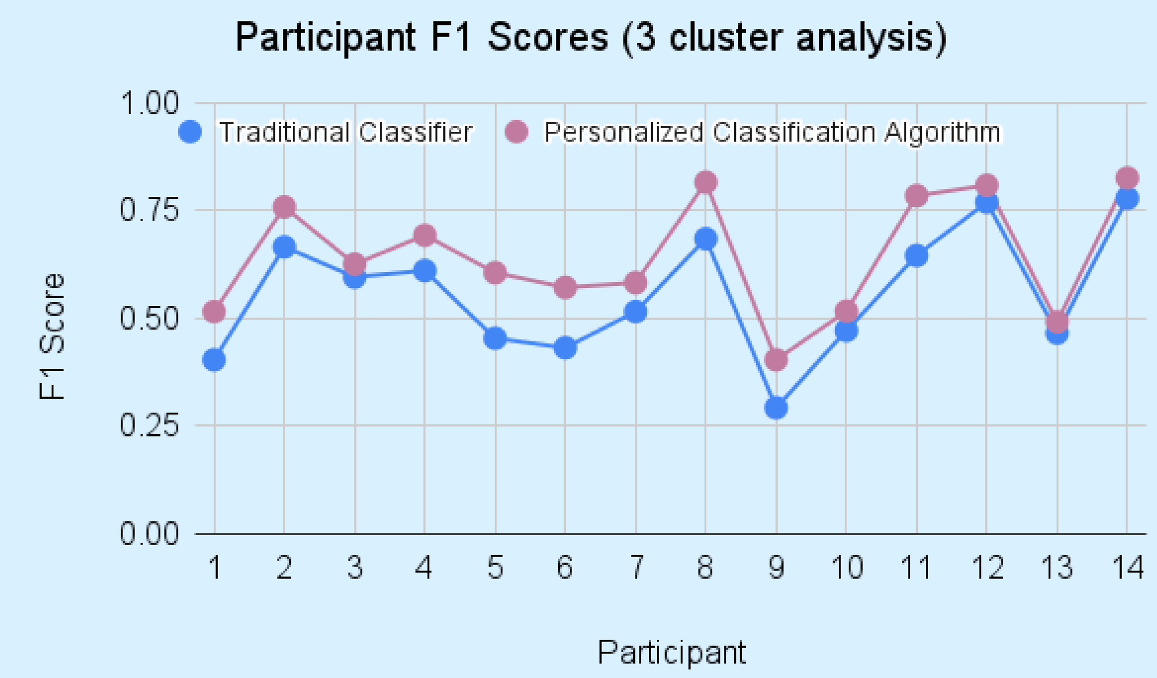
Results



Average F1 scores showed that the proposed algorithm modestly outperformed traditional classifiers

F1 score: performance evaluation metric for ML models that combines precision and recall. F1 score ranges from 0 to 1 (1 is best)

Key Takeaways:

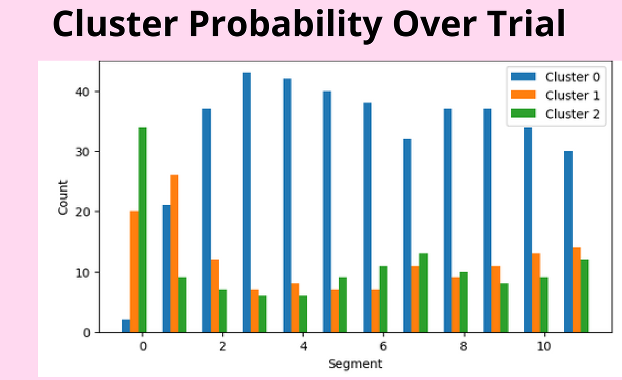
- No degradation in BCI performance for any participant
- Improvement is greater for some participants than others. Further analysis needed to determine reasoning fo this.

Conclusions and Next Steps

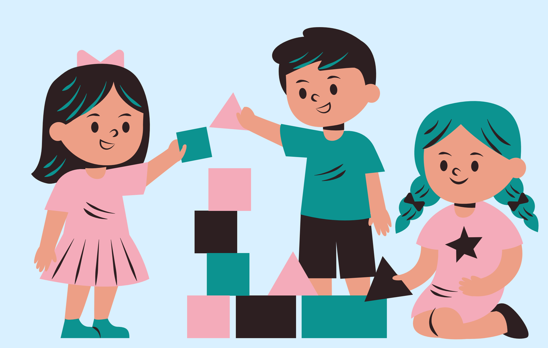
This analysis yields insight into the task performance characteristics of low-performing users. These **insights could guide personalized BCI design practices** that would improve their clinical feasibility.

Next Steps: Many participants transition into task-irrelevant pattern states at the beginning of a motor imagery trial. We can refine the algorithm to look at specific time windows during the trial when making classifications

Cluster Probability Over Trial



Relevance to HB Clients



Child autonomy and empowerment

BCIs can enable children with disabilities to interact with their environments using their brain alone.

Increasing BCI accessibility to a wider demographic of children

These hierarchical classification algorithms can enable more people to successfully use BCIs

Supportive Housing Experiences of Residents with Developmental Disabilities

Sunner, R.,[1] Cox, E.,[1] Ross T.[1,2,3]

[1]Bloorview Research Institute, [2]Department of Geography & Planning, University of Toronto, [3]Rehabilitation Sciences Institute, University of Toronto

Background

- People with developmental disabilities (PWDD) experience **long waitlists**[1] for supportive housing due to a short supply[1] of residences
- PWDD may experience unmet needs[1,2] and **unsafe** living conditions in other housing environments
- Little is known about how PWDD experience supportive housing

Research Question

How do PWDD experience their supportive housing environments?

Methods

- Twenty-eight residents living in two Toronto-based supportive housing residences participated in art activities and interviews
- Interview data was thematically coded[3] using NVivo software

Supportive housing designs and operations require improvement to support resident independence, interaction, and wellbeing

Preliminary Results

- Engaging **resident input** could enhance supportive housing designs and operations, and improve resident independence
- Improved unit **safety design** can enhance resident access and independence
- Improved **common space** access can create desired social opportunities for residents
- Residents desire enhanced **programming** that promotes belonging

Conclusion

- Design and operational improvements can be made to enhance resident independence, safety, interaction, and belonging
- Resident perspectives should be included in the planning, design, and operation of supportive housing residences

Relevance to Holland Bloorview

- Findings will help to prepare clients and their families for transitions into adulthood
- Supports engagement with perspectives of PWDD (e.g., co-creation) and promotes IDEAA values

Acknowledgements

Thank you to the Ward Family and the New Frontiers in Research Fund for supporting this research.

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EPIC Engagement & Planning for Inclusive Communities

University of Toronto

AI-augmented Personalized Medication Recommendation for Neurodivergent Children

Ricky Zhang, Harshit Bokadia, Dr. Azadeh Kushki

Background

While medications can improve **outcomes** in neurodivergent children, there are no biological **markers** to guide selection. Determining the appropriate medication remains a significant clinical **challenge**.

Objective

Implement an AI-based decision model to generate medication recommendations for stimulant, antidepressant, and antipsychotic drug classes. Additionally, identify and evaluate biases in this model.

Method

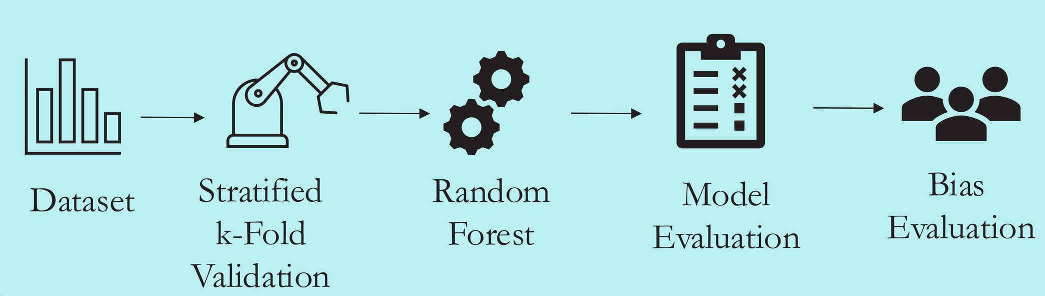
Datasets

Holland Bloorview Psychopharmacology Program (PPP)

n = 277 | Mean age = 10.50 years | 83.75% male | 26% intellectual disability

Province of Ontario Neurodevelopmental Disorder (POND)

n = 499 | Mean age = 10.82 years | 68.73% male | 73.34% white | 8.82% intellectual disability



AI demonstrates potential in the medication prescription of neurodivergent children

Holland Bloorview

Kids Rehabilitation Hospital

POND NETWORK

Province of Ontario Neurodevelopmental Disorders

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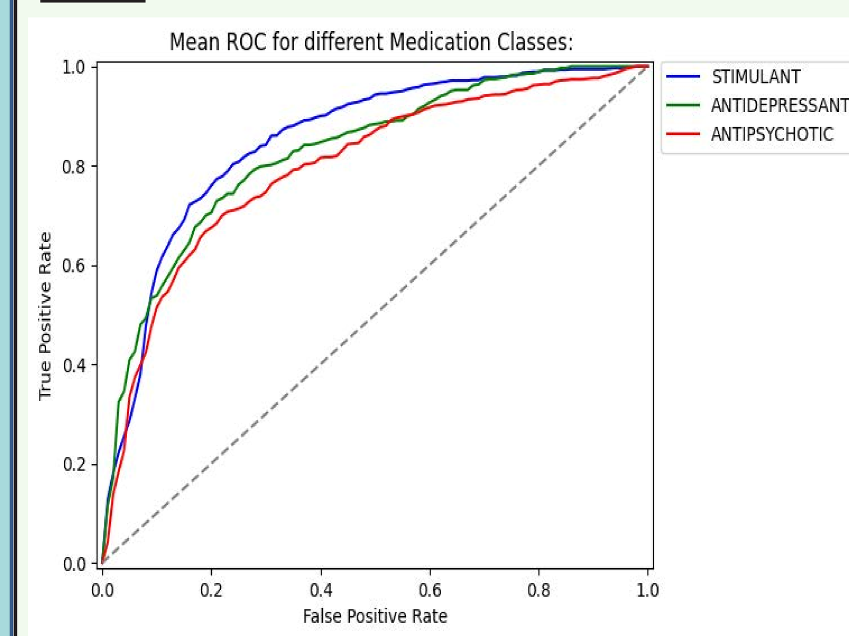
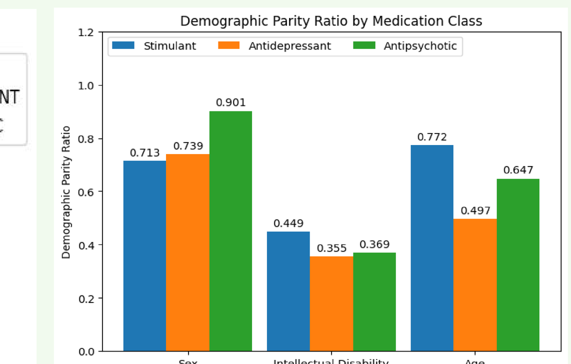
Results

PPP





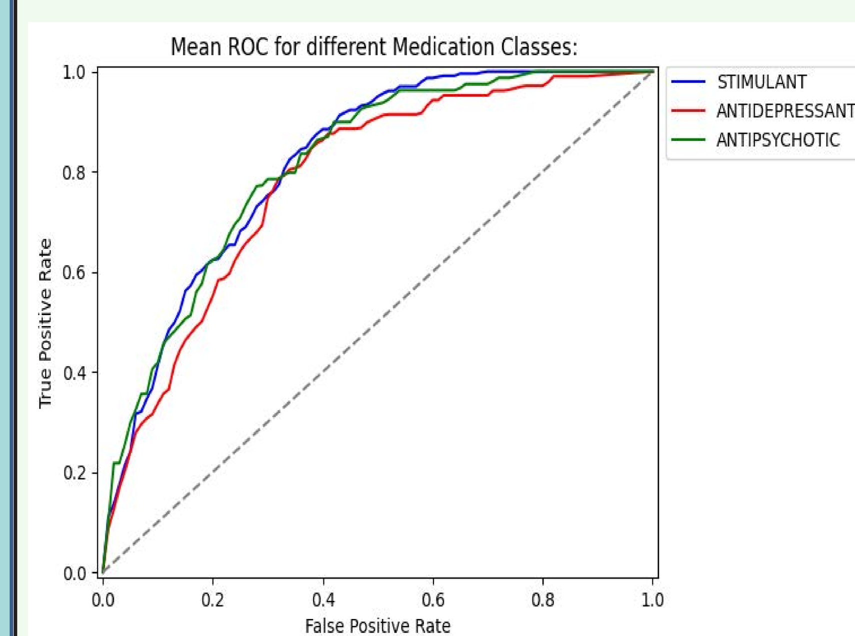
Best Predictive Features:

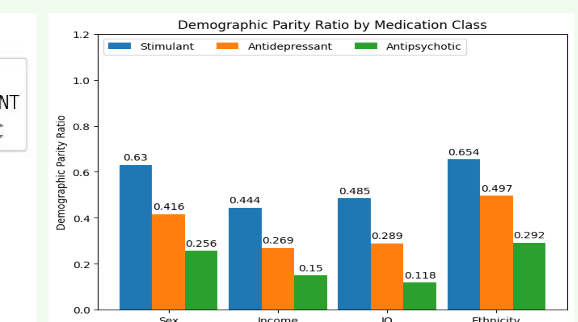
Stimulant: Adhd

Antidepressants: Anxiety

Antipsychotics: Age

POND





Best Predictive Features:

Stimulant: Adhd

Antidepressant: Age

Antipsychotics: ABAS Social Composite Score

Good to excellent ROC-AUC (> 0.75) across all drug classes

Significant biases present, particularly for intellectual disability.

Conclusion & Relevance

Model demonstrates good to excellent performance in predicting medication prescription of neurodivergent children. Additionally, significant biases are found within the model.

These findings demonstrate...

- **Potential** for AI medication prescription
- **Reduced** trial-and-error and risk
- **Avenues** for future research

Next Steps

- Identify **interest** from clinicans and familes
- Development of **bias-aware** models
- Prediction of **specific** medications

Association Between Financial Barriers to Care and Caregiver Burnout

Rana, S. [1,3], Lenz, S. [1,2], Rapley, J. [1], Baribeau, D. [1]
1) Bloorview Research Institute
2) University of Toronto
3) York University

Background

Caregivers of children with neurodevelopment disorders (NDDs) face an increased risk of burnout, leading to adverse health outcomes.[2]

BUT...

Many intervention programs have substantial **out-of-pocket costs**, creating **financial barriers** for families in accessing care.[1]

Objective

Find out the prevalence of financial barriers to accessing care, and its association with the experience of caregiver burnout.

WHO: Children aged 6-18 with NDDs

WHERE: Holland Bloorview Psychopharmacology program

HOW: Documented in medical records by the treating clinician during the consultation visit

Methods

1. Review medical records from children with NDDs and complex behavioural care needs seen in the Psychopharmacology program between 2019-2023.
2. Define variables.
   - **Financial barriers:** Clinician documentation and social services received (e.g., ACSD, Ontario Works, or Ontario Disability Support Program).
   - **Caregiver burnout:** Clinician documentation and circumstantial evidence.
3. Conduct Chi-Square contingency test to determine whether an association is present.
4. Conduct a multivariate logistic regression, and test for confounding variables.

Challenges

Clinician did not always include whether client was facing financial barriers to care. Burnout was also not always explicitly stated.

Included those cases where burnout or financial barriers were not explicitly stated; but understood based on the description of the situation.

Missing Data

Financial barriers to care reported as missing information: 18%

Caregiver burnout reported as missing information: 2%

Table 1: Demographic Data as per First Visit

	N	Percentage	Mean
Age	343		10.17
Sex			
Male	282	82.22%	
Female	61	17.78%	
Diagnosis			
Autism	312	90.96%	
ID	93	27.11%	
Genetic Condition	35	10.20%	

Financial barriers to care are significantly associated with caregiver burnout in families with children with neurodevelopmental disorders (NDDs).

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Results

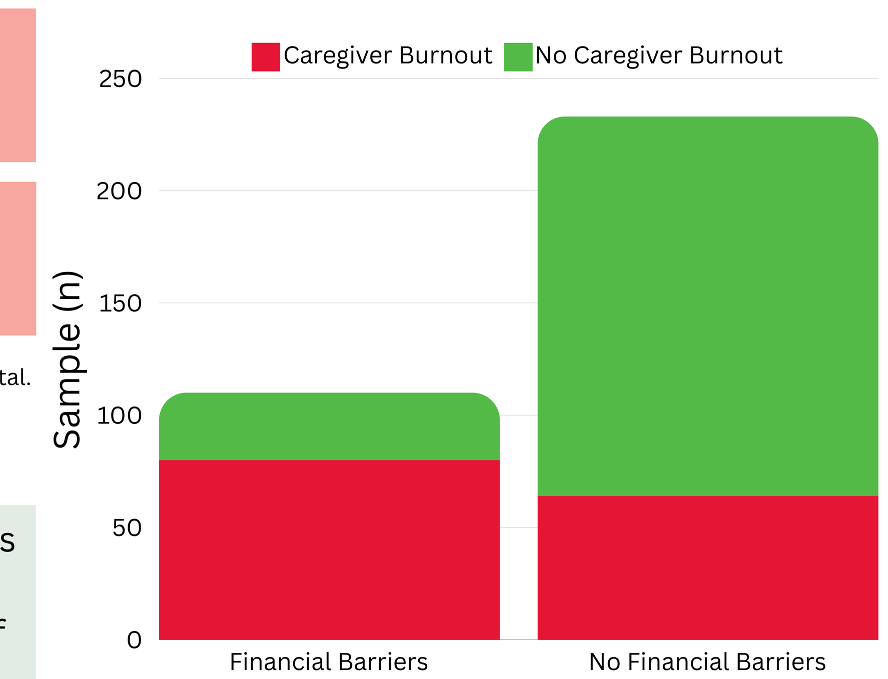
42% of caregivers were experiencing burnout.

32% caregivers reported financial barriers to care.

Missing data was included in denominator making up total.

$X^2 = 62.841; p < .0001$

Strong association: financial barriers may be an important contributor to caregiver burnout among families of children with NDDs.



What if something else is contributing to burnout?

Age, presence of aggressive behavior, and presence of an intellectual disability were hypothesized to be potential confounding variables

Table 2: Univariate and Multivariate analysis of different predictors

	Univariate		Multivariate	
Predictor	**OR (95% CI)**	**P-value**	**OR (95% CI)**	**P-value**
Financial Barriers to Care	7.04 (4.28-11.86)	<0.001	6.31 (3.79-10.75)	<0.001
Presence of Aggression	3.43 (2.03-5.97)	<0.001	2.61 (1.47-4.77)	0.001
Intellectual Disability	1.73 (1.10-2.72)	0.02	1.45 (0.85-2.48)	0.2
Age	0.96 (0.77-1.19)	0.7	0.96 (0.75-1.24)	0.8

The multivariate model showed adequate discrimination with an AUC of 0.76. **Financial barriers were associated with the greatest odds of parent burnout.**

Conclusion

Many families of children with NDDs face financial barriers to care, closely associated with caregiver burnout. addressing these financial challenges is crucial to supporting families.

Relevence

Comprehensive care should include support for caregivers' mental health, respite access, and financial resource navigation to reduce caregiver burnout.

Systems are needed to ensure equitable access to therapies and services for children with NDDs, and gaps in demographic data need to be addressed.

Acknowledgements

I would like to thank Danielle, Jesiqua, Christina and Sophia for being such a wonderful team. In addition, thank you to the WARD Summer Summer Student Research program, Bloorview Research Institute, and the Autism Research Centre for making this research possible.

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2) Lindly, O. J., Shui, A. M., Stotts, N. M., & Kuhlthau, K. A. (2022). Caregiver strain among North American parents of children from the Autism Treatment Network Registry Call-Back Study. Autism : the international journal of research and practice, 26(6), 1460–1476. https://doi.org/10.1177/13623613211052108

Understanding the experiences and disparities of sex/gender minoritized (SGM)-youth with disabilities: a scoping review

Oliver T. [1], Leo S. [1], Slothouber V. [1], Lindsay S. [1,2]

Background

SGM youth with disabilities → Effect on experiences → Impact on well-being/ quality of life

SGM youth with disabilities endure increased discriminative disparities relative to non-disabled SGM youth

Listening to outcomes and experiences of youth with intersecting marginalized identities

Research Question:
What are the experiences and disparities of sex/gender-minoritized youth and young adults with disabilities?

What we know

Factors affecting SGM youth with disabilities experiences

Type of disability → Type of SGM → Extent of support/ resources → Access to safe spaces

Methods

Search Strategy:

- Six databases (Ovid Medline, Healthstar, Embase, PsychInfo, Scopus and Web of Science)
- Two researchers screened titles/abstracts
- Key terms: 'sex-gender-minoritized youth', 'disabled and LGBTQ+ youth', 'lived experiences', 'mental health', 'ASD', 'intersectionality'

Identification of studies (n=3401) → Duplicate references removed (n=1413)

Titles and abstracts screened (n=1983) → Studies excluded (n= 1929)

Full-texts screened (n= 39) → Studies excluded: (n= 16)
a) fails to meet inclusion criteria (n=4)
b) unspecified findings (n=5)
c) absence of both SGM and disability experiences (n=10)

Studies included (n= 23)

Sex and gender minoritized youth with disabilities often experience negative impacts on health and barriers to expressing their identity

Acknowledgements

Thank you to the Ward family for funding the WARD summer student program. This research was funded, in part by SSHRC and the Kimel Family Fund.

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SSHRC CRSH
Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada

University of Toronto

1. Bloorview Research Institute, 2. University of Toronto

Results

30.4% of studies included family and/or parental concerns

69.6% of studies included youths' perspectives

Participant Characteristics (Ages 12-25)

Disability: identified in studies
- 69.56% of studies contained ASD participants

Prevalent disabilities in studies:
- Autism-spectrum-disorder
- Attention-deficit-hyperactivity-disorder
- Anxiety disorders
- Depression
- Cognitive disabilities
- Intellectual disabilities
- Physical disabilities

Gender identity: in studies
- Most prevalent gender identities in studies were trans and gender-nonconforming

Prevalent gender identities in studies:
- Transgender
- Transmasculine
- Transfeminine
- Non-binary/gender non-conforming
- Genderqueer
- Agender
- Cisgender female and male

12 Qualitative studies,11 Quantitative studies

Themes: Experiences of SGM youth with disabilities (n=23)

Exploration and expression of sex/gender identity	Adverse experiences	Impact on quality of life & mental health	Coping and intervention techniques
1. Communication barriers 2. Negotiation of identity 3. Disclosure vs non-disclosure 4. Invalidation	1. Stigma and discrimination 2. Harassment 3. Bullying 4. Victimization 5. Relationship abuse	1. Substance abuse 2. Suicidal behavior 3. Suicidal ideation 4. Restricted eating 5. Increased anxiety	1. Effective mental health treatment 2. Peer/social support 3. Family support interventions 4. Safe environments
High presence of **gender delegitimization**, coming from professionals, caregivers, and family members	SGM youth with disabilities experience high rates of **social stigma**, and **identity-based discrimination**	Due to reoccurring inequity, youth experience high rates of **suicidal ideation**	Increased well-being for SGM youth has been correlated with **peer support groups**, and **positive family interventions**

Conclusions and Next Steps

Several disparities and barriers exist for SGM youth with disabilities that **affect their well-being** → Research should explore the **prolonged effects** of these negative experiences

Relevance to Holland Bloorview

Staff and volunteers should account for the differing perspectives and experiences of co-occurring marginalized identities among clients + Addressing all identities of youth allows staff to situate the varying needs and supports youth and families require + Collecting SGM-disabled based experiences from clients and families to understand complexity of identity

Assessing Facilitators and Barriers to Pediatric Autism Assessment Using an Implementation Science Framework

Wakif, Z., Kanigsberg, L., Ferguson, G., Penner, M; Project ECHO AuDIO Team

Background

Autism = neuro-developmental condition, **early diagnosis** is key for care

Feelings and frustration around care explored, **lack of implementation science framework** lens to autism assessment

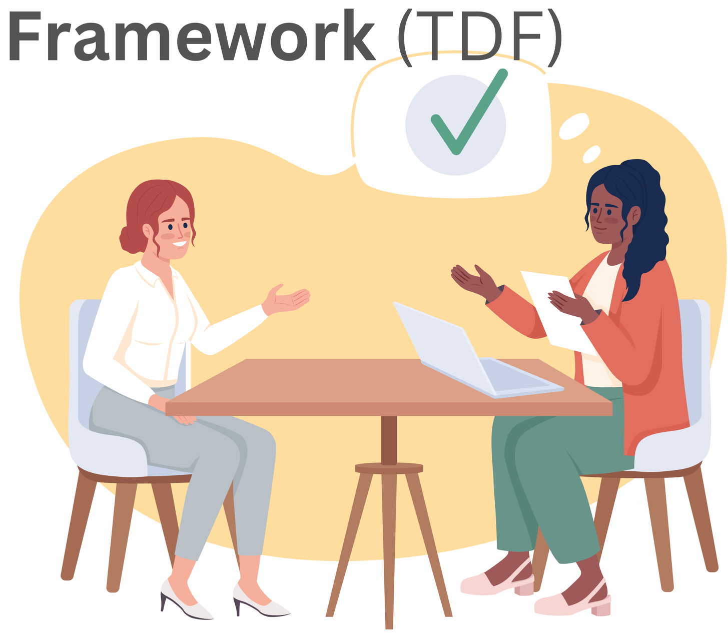
Objective

Use an **implementation science framework** to assess **diagnostic barriers and facilitators** pediatricians across Ontario face to help **facilitate appropriate strategies**

Method

Seven community general pediatricians (six women; one man) with a range of years in practice and autism-specific training participated across three **focus group/dyad interviews in Ontario**

Transcripts coded and analyzed using **Theoretical Domains Framework** (TDF)



Themes for diagnostic facilitators and barriers identified via **deductive thematic analysis** through NVivo

Pediatricians identified their knowledge and skills to diagnose autism while also noting many contextual barriers to this work

SCAN ME

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Preliminary Results

Key TDF Domains	Key Constructs	Examples
Knowledge	Knowledge; procedural knowledge; knowledge of task environment	**Facilitator:** *"So I think foundational to all of it is a very clear understanding of what the criteria are…" (Transcript 3)* [Construct: Knowledge]
Skills	Skills; competence; interpersonal skills	**Facilitator:** *"… I think as a skill base, one has to be able to have the comfort to look at developmental abilities in general, to look at intellect and then also to factor in the mental health and that's a huge skill set if you're gonna diagnose autism across the ages." (Transcript 1)* [Construct: Competence]
Memory, attention, and decision process	Memory; attention; decision making	**Barrier:** *"The extremes of age are tough. So if they're really young, and I tend to be judicious, like I say that like this is a lifelong diagnosis. I really want to be sure…" (Transcript 1)* [Construct: Decision making]
Environmental context and resources	Environmental stressors; resources/material resources; barriers and facilitators	**Barrier:** *"Well, and even in families sometimes where they're maybe not inclined to want to diagnose this or not ready for that, I would again love to be able to access the service but not feel that pull that we need that diagnosis to do that, right? So having a more collaborative approach, we could say, listen, we can do some early intervention, we don't have to agree on that part just yet, but let's do some early intervention…" (Transcript 3)* [Construct: Environmental stressors]

Facilitators: supportive networks, experience, interest, high confidence, increased exposure to assessment

Barriers: inflexible policies, shared frustration, burnout, lack of resources, and poorly paid/unpaid labour

Conclusion

Remaining **analysis and thematic map are underway** for Ontario data

Final results to include **multi-provincial data** for diagnostic facilitators and barriers

Next Steps

Influences policy makers and clinicians **implement changes**

Development of **toolkits** helps clinicians

Conduct and analyze other site/provincial interviews to identify **across-site and site-specific needs** for autism **assessment and ongoing integrated care**

Relevance

Influences necessary **policy changes**, toolkits will encourage **more assessments**

Ultimately improves **early diagnosis and resource access** for families and autistic youth

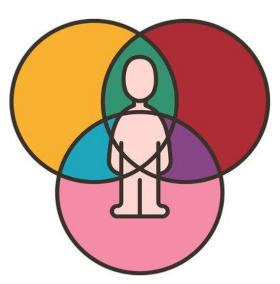
Characterizing sociodemographic biases in adaptive functioning data in a cohort of neurodiverse children.

Zuhair Qureshi[1], Harshit Bokadia[2], Azadeh Kushki[2,3]

[1] McMaster University Integrated Biomedical Engineering and Health Sciences
[2] Autism Research Centre, Bloorview Research Institute
[3] University of Toronto, Institute of Biomedical Engineering

Background

Adaptive functioning: the ability to independently perform skills of everyday life.



General Adaptive Functioning

Social Functioning | Conceptual Functioning | Practical Functioning

Sociodemographic factors often bias clinical results.

Objective

To characterize **sociodemographic biases** in **adaptive functioning scores** in the **Province of Ontario Neurodevelopmental (POND)** Network dataset.

Methods & Analysis

Methods

Filter POND entries for non-null:

- Mean age = 10.29 ± 4.33 years
- n_{total} = 1254

General Adaptive Composite (GAC) Score	Socio-economic status	Sex	Ethnicity
Above 70 = 55%	Above median income = 64%	Male = 70%	White = 85%

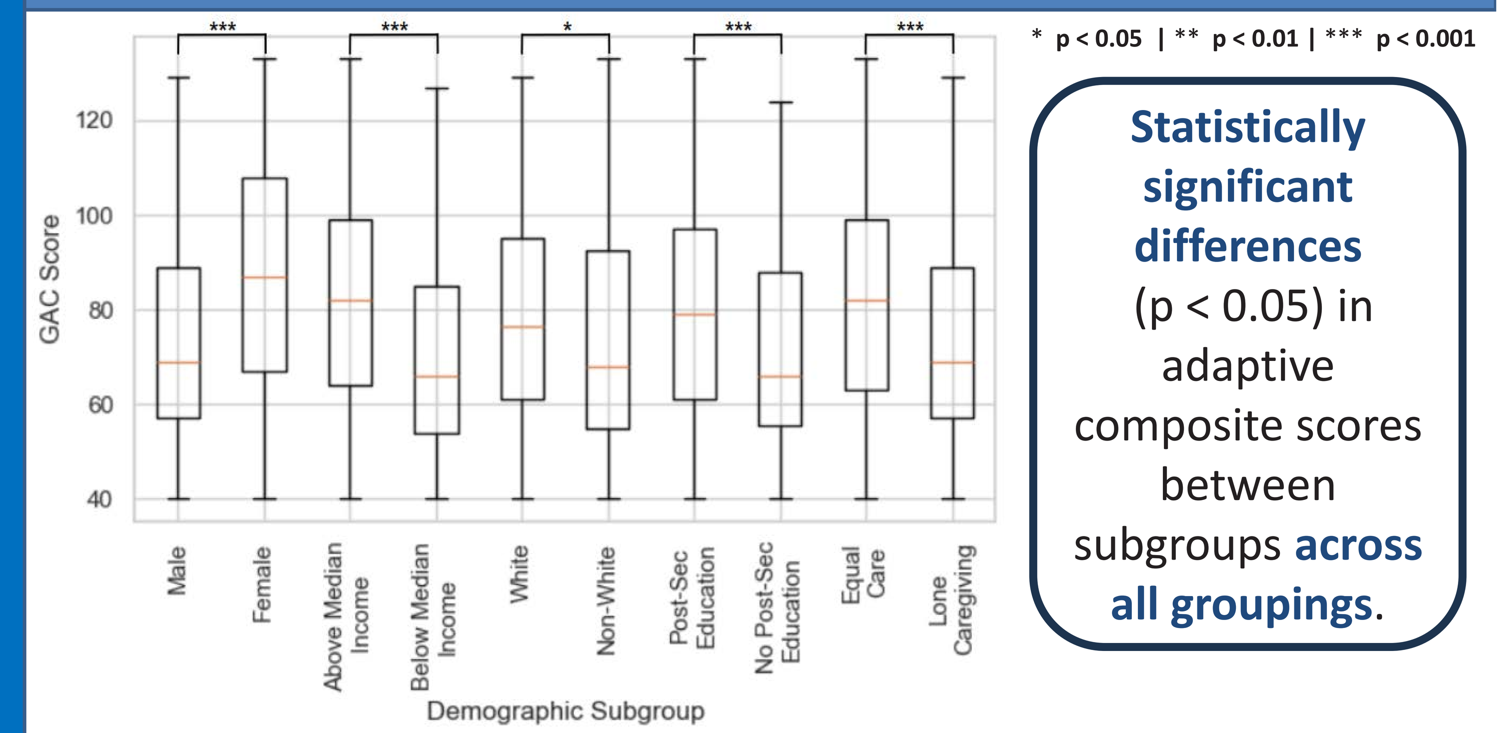
Analysis

Significance Testing → Mann Whitney Test between GACs of listed subgroups.

Machine Learning Model → XGBoost model + 15-fold cross-validation (demographic data) → Predictions → Feature importance + Bias analysis

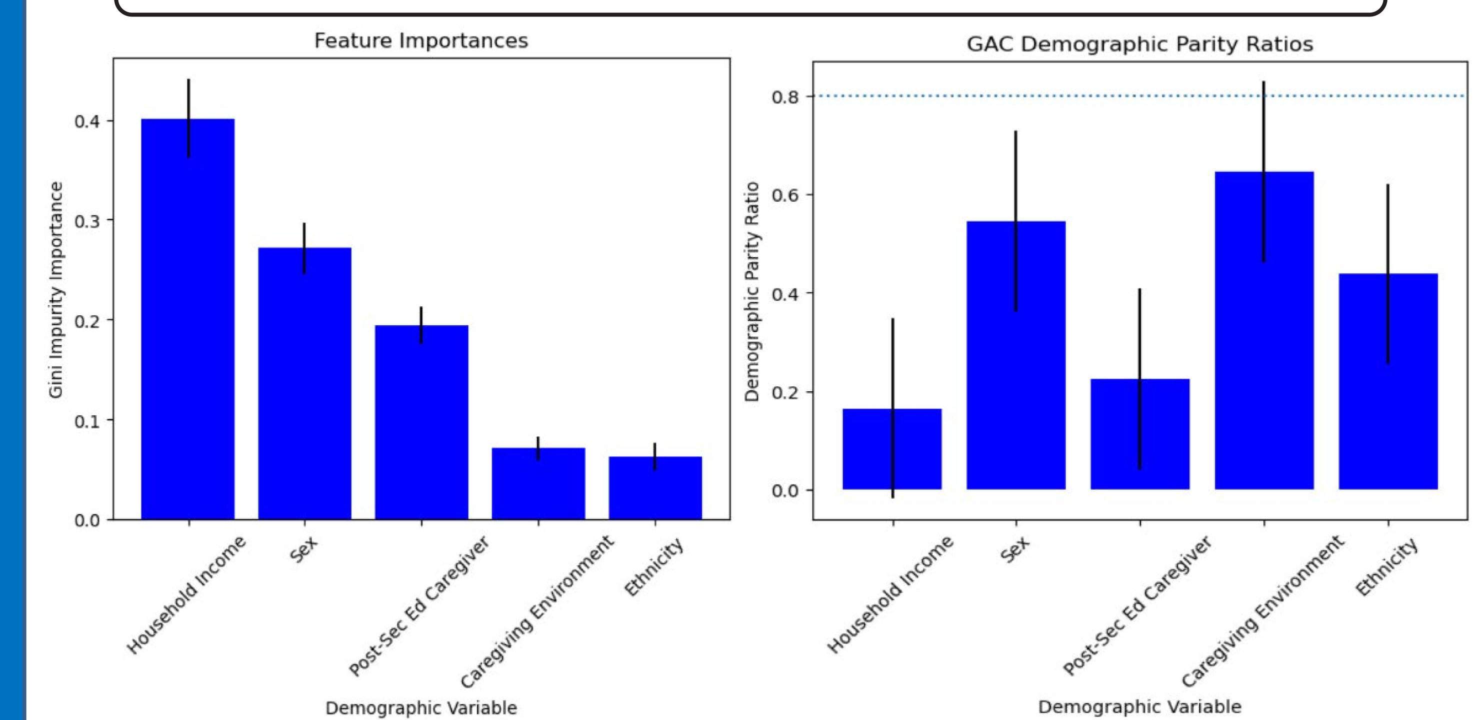
Adaptive functioning scores are biased by sociodemographic factors including socioeconomic status, sex, and ethnicity.

Results



Statistically significant differences ($p < 0.05$) in adaptive composite scores between subgroups **across all groupings.**

Large disparities in adaptive functioning between subgroups



Conclusion & Relevance to Holland Bloorview

Significant biases revealed in adaptive functioning scores between subgroups based on socioeconomic status, sex, and ethnicity.

These findings provide….

- Precision health insights into low adaptive functioning …informs Bias-aware approaches to supporting families; next steps: Study demographic interactions
- i.e. Sociodemographic correlates; Risk factors
- e.g. Personalized client profiles

Acknowledgments

I would like to extend my gratitude to my mentor, Harshit Bokadia, and my supervisor, Dr. Azadeh Kushki, as well as the Ward Family and Bloorview Research Institute for making this project conceivable.

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