

AUTISM COUNCIL MEETING MINUTES
Friday, February 23rd, 2024
9:00 am – 12:00 pm

COUNCIL MEMBERS PRESENT	ORGANIZATION, REPRESENTATION
Dr. Amy Matthews, LP, BCBA	Grand Valley State University, State-funded Initiatives
Dr. Colleen Allen, Ph.D.	Autism Alliance of Michigan, a Non-Profit Organization serving those with ASD
Dana Lasenby, MBA	Oakland Community Health Network, Pre-Paid Inpatient Health Plans/Community Mental Health Service Programs
Emily DeLaGarza	Michigan Department of Insurance & Financial Services
Dr. Jacob Daar, BCBA	Northern Michigan University, State Universities
Dr. Jeanette Scheid	MDHHS Children’s Services Administration
Jenny Piatt, MA	Michigan Rehabilitation Services, Employment Services
Krista Boe, M.A., BCBA	Acorn Health, Certified Behavior Analysts
Martin Baum, J.D.	Parent, ASD Community
Phil Kurdunowicz, MHSA	Bureau of Children’s Service Coordinated Health Policy & Supports
Rebecca McIntyre, MEd	Michigan Department of Education
Raymie Postema	Michigan Department of Health & Human Services, Recipient Rights
Dr. Neelkamal Soares	Western Michigan University Homer Stryker MD School of Medicine, Health Care Providers
Frank Vaca	Self-Advocate, ASD Community
Brian Debano, MPA	Department of Licensing and Regulatory Affairs
COUNCIL MEMBERS EXCUSED	ORGANIZATION, REPRESENTATION
Dr. Steven Tunncliff, Ph.D.	Genesee ISD, Intermediate School Districts and Local Schools
MDHHS STAFF PRESENT	MDHHS REPRESENTATION
Dr. Erika Dianis, PsyD, LP	Bureau of Children’s Service Coordinated Health Policy & Supports
Heather Glidden, LBSW, QJDP, MS	Bureau of Children’s Service Coordinated Health Policy & Supports
Patricia Neitman, MS, LLP	Bureau of Children’s Service Coordinated Health Policy & Supports
Marina Wyrzykowski*	Legislative Affairs

Dr. Mary Luchies, Ph.D., LP, BCBA, LBA	Bureau of Children’s Service Coordinated Health Policy & Supports
Maya Bryant, MPH, NASM-CPT	Bureau of Children’s Service Coordinated Health Policy & Supports
Alicia Cosgrove	Bureau of Children’s Service Coordinated Health Policy & Supports

* Indicates the member joined virtually

- Multiple guests also attended in person and virtually.

CALL TO ORDER

The Autism Council meeting was called to order by Amy Matthews at 9:05 am. A quorum was present for the meeting.

ROLL CALL

A roll call of Council members and MDHHS staff was completed.

APPROVAL OF PREVIOUS MINUTES

Dr. Scheid called for a **MOTION** to approve the February minutes. Krista Boe made a **MOTION** to approve the February minutes. Amy Matthews **SECONDED** the motion. The **MOTION** carried.

PUBLIC COMMENT

Nothing to report.

Michigan Department of Health and Human Services (MDHHS) UPDATES

Financial Operations Administration-MDHHS Budget: Maya Bryant reported, see Appendix I for the update.

Legislative Update: Marina reported on the bills in Appendix II of the meeting minutes.

- Discussion
 - Question regarding Senate Bill 227 and whether it will be reintroduced
 - Legislative response – there could be some difficulty with the 52-52 split
 - Is the dept tracking House Bill 5114 – expansion of scope?
 - Yes, it’s being monitored in House policy
 - Some support from hospital systems because it supports access to their activities
 - At this point MPS likely opposes it
 - Concern about the support for licensing and oversight

Bureau of Children’s Service Coordinated Health Policy & Supports (BCCHPS)

- IDD and ASD Services Section
 - Working through policy updates for annual re-evaluation and updates for autism
 - QBHP Policy and clarifications which is slated to end in 2025
 - Working with Bureau partners for data collection, about 8,000 are receiving ABA treatment
 - Working to set training with Dr. Brooklier for the Autism Diagnostician Training Series
 - Project with MDE

- MichiCANS a tool for – 8-21-year-olds for severe emotional disturbances and developmental disabilities which will help to assess children and young adults, the decision support model may be able to be presented at a future meeting
- Waitlists for services are happening for families which happen for various reasons – ex. Provider of choice is not available, service isn't available, in-home care is not yet available – PIHPs do reach out to families periodically to alert them of the available services
- Some research is being done to see barriers to access to services from AAOM at a local level

MDE Update

- ABA services training – 327 people accessed services in January
- More investigation into mat therapy as an alternative to seclusion restraint
- Discussion:
 - It appears that mat therapy lacks skill-building

LEO/MRS Update

- **Students are encouraged to explore education and career pathways during Career and Technical Education Month** – on February 8, a press release recognizing [February as CTE Month](#).
- **New extension campuses will expand technical education opportunities for Michiganders with disabilities** – on February 5, a press release announcing [two new extension campuses for Michigan Career and Technical Institute](#).
 - Expanding access to the college's vocational rehabilitation services to students in Kalamazoo and Livingston counties.
 - The Northside Association for Community Development will provide Certified Nurse Assistant training in Kalamazoo while Torch 180, a non-profit café and coffee shop in Fowlerville, will offer culinary training to individuals who are eligible for services through Michigan Rehabilitation Services (MRS).
- **Gov. Whitmer announces funding to provide life-changing career pathways through Registered Apprenticeships** – on February 14, press release announcing recipients of \$1M in [competitive grants to provide underrepresented individuals with access to Registered Apprenticeship](#).
- **March 1st – National Assistive Technology Awareness Day**
 - Please see below on public release of information from LEO-MRS
 - Under the Assistive Technology Act of 1998, the Michigan Assistive Technology Program (MATP) under Michigan Disability Rights Coalition ([Assistive Tech Program – Michigan Disability Rights Coalition \(mymdrc.org\)](#)) implements the Assistive Technology Federal Award/Grant, MRS is the lead agency dispersing funds and support activities to the grant and MDRC.

Department of Insurance and Financial Services (DIFS)

- Emily DeLaGarza – no update

Old Business

- Action Items from previous meeting:
 - Still working to get more information from Medicaid and Priority Health

- Angel Sense device – in conversation with BPHASA
 - Working to see how it may be covered through Medicaid
- Research any insurance claims related to Angel Sense/GPS
 - Jacob – asked families that utilize a similar device – it was provided by the police and it only works in the local area
- Review and approval of the 2023 Annual Report
 - Phil motioned to approve the annual report and Dana seconded, the motion carried

New Business

- Presentation from Katie Oswald
 - See slides in Appendix III of meeting minutes
- Presentation from Childhood Lead Poisoning Prevention Program - DHHS
 - Exploring Interventions to Decrease Lead Exposure in Children with Autism and Pica
 - See slides in Appendix IV of meeting minutes
 - Discussion:
 - Education from providers to parents on dangers of lead poisoning, often lead is not a concern when some symptoms are seen until hospitalization occurs

Member Updates

- Psychiatric hospitals running programs for IDD and ASD
- AAOM’s upcoming parent conference
- Jacob – program for those in grad school for LEND program

Action Items			
<i>Status (Open) (Complete)</i>	<i>Description</i>	<i>Owner</i>	<i>Target Date</i>
Complete	Continued research into Angel Sense device	Phil	Ongoing
Complete	Continued conversation around Medicaid Health Plan network issues and mental health professional expansion.	Phil, Dr. Soares	Ongoing
Open	Council post-meeting email	Maya	3/1/2024
Open	Autism Self-Advocate Agenda Planning	Planning Group	Ongoing
Open	Council to Review the 5-Year Plan	All Council Members	Ongoing

Adjourn

Amy Matthews adjourned the meeting at 12:05pm. The next Autism Council meeting will take place on December 15, 2023, in Lansing.

Frank motioned to adjourn the meeting; Amy adjourned at 12:00 pm.

Appendix I Budget Update

<div style="text-align: center;"> <h2 style="font-size: 2em; margin: 0;">Grant and Budget Update</h2> <p style="font-size: 0.8em; margin: 5px 0;">Division of Access Standards, Service Array, and Policy</p> </div>	<p style="text-align: right; font-weight: bold;">The executive branch has submitted its proposed budget and sent it to the respective chambers for deliberation.</p>						
<p>New Initiatives to be Funded:</p> <ol style="list-style-type: none"> 1. Assistance to Low-Income Families <ol style="list-style-type: none"> a. \$4.5 million Emergency Housing Support for Families Engaged in Child Welfare 2. Supporting Child Welfare Capacity <ol style="list-style-type: none"> a. \$38 million to restructure rates ensuring needed beds in residential facilities are provided to children 3. Behavioral Health Capacity Improvements 4. Restructuring of Michigan Medicaid <ol style="list-style-type: none"> a. \$1.8 million (general fund) to recognize the elimination of monthly MiChild premiums 5. Public Health and Safety <ol style="list-style-type: none"> a. \$2.5 million for access to mental health services (general fund). 	<p>Behavioral Health Capacity Improvements Include:</p> <ol style="list-style-type: none"> 1. \$193.3 million to expand Michigan's Certified Community Behavioral Health Clinics (CCBHC) demonstration program 2. \$36.1 million to increase rates for behavioral health services provided through Medicaid health plans 3. \$8.3 million to establish Medicaid reimbursement for peer-provided substance use disorder services 4. \$7.3 million for the Michigan Crisis and Access Line (MiCAL) 5. \$4 million to enhance gambling prevention and treatment services 						
<p style="text-align: center;">Funding for Autism Services</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="text-align: center;">FY24 Appropriation</td> <td style="text-align: center;">\$279,257,100</td> </tr> <tr> <td style="text-align: center;">FY25 Projection</td> <td style="text-align: center;">\$330,231,300</td> </tr> <tr> <td style="text-align: center;">FY26 Projection</td> <td style="text-align: center;">\$330,231,300</td> </tr> </table>	FY24 Appropriation	\$279,257,100	FY25 Projection	\$330,231,300	FY26 Projection	\$330,231,300	<p style="text-align: center;">Boilerplate Items</p> <ul style="list-style-type: none"> • Included: <ul style="list-style-type: none"> ◦ Section 913 <ul style="list-style-type: none"> ▪ From the funds appropriated in part 1 for Behavioral Health Program 8 administration, the department shall allocate \$1,025,000.00, for the autism navigator program. The department shall require any contractor receiving funds under this section to comply with performance-related metrics to maintain eligibility for funding. ▪ FY24 1 one-time allocation of an additional 1 Mil that was not continued in FY25 • Excluded: <ul style="list-style-type: none"> ◦ Section 924 <ul style="list-style-type: none"> ▪ Maintenance of fee schedule for autism services - Expenditures used for rate setting shall not exceed those identified in the fee schedule. ▪ Section 960 <ul style="list-style-type: none"> • Historical requirements for Medicaid autism services <p style="text-align: center;">Department has the authority to act on the excluded items without them written into the boilerplate or has completed the related items.</p>
FY24 Appropriation	\$279,257,100						
FY25 Projection	\$330,231,300						
FY26 Projection	\$330,231,300						

Appendix II Legislative Update

[House Bill 4101](#) (VanderWall) – *Modifies temporary licensing of speech-language pathologists* – LARA/DHHS Co-Leads, 2/20/24 Substitute H-2 adopted, placed on third reading in the House

[House Bill 4131](#) (Liberati) – *Modifies coverage for health care services provided through telemedicine* – DIFS Lead, 2/7/24 Received hearing in Senate Health Policy Committee

[House Bill 4213](#) (Morse) – *Provides definition of distant site for telemedicine visit* – DHHS/LARA Co-Leads, 2/7/24 Received hearing in Senate Health Policy Committee

[House Bill 4523](#) (Hope) – *Modifies eligibility for mental health court for those with violent offenses* – SCAO/AG/LEGAL Co-Leads, 2/20/24 Reported from Senate Civil Rights, Judiciary & Public Safety Committee with an S-1 substitute

[House Bill 4579](#), [4580](#) (Price, Brabec) – *Requires reimbursement rate for telehealth visits to be the same as office visits* – DIFS/DHHS Co-leads, 2/7/24 Received a hearing in Senate Health Policy Committee

[Senate Bill 227](#) (Lauwers) – *Modifies emergency safety intervention in a children's therapeutic group home* – DHHS/LARA Co-Leads, 11/11/23 Recalled to the House, 1/17/24 Taken up by the House again to adopt H-1 substitute, 1/18/24 Defeated in the House

New:

[House Bill 5391](#) (Friske) – *Provides notification to the public by text message of a missing senior or vulnerable adult* – MSP/LEGAL Co-Leads, Referred to House Government Operations Committee

[House Bill 5397](#) (Rogers) – *Provides notification to the public by text message of a missing senior or vulnerable adult* – MSP/LEGAL Co-Leads, Referred to House Health Policy Committee

[Senate Bill 685](#) (McCann) – *Requires health insurers to provide coverage for dispensing a 90-day refill for maintenance prescriptions* – DIFS/DHHS Co-Leads, Referred to Senate Health Policy Committee

[Senate Resolution 88](#) (Santana) – *A resolution to recognize February 2024 as School-Based Health Care Awareness Month*

Appendix III Statewide Advisory Committee

Issues Impacting Autistic Adults & the need for a Statewide Advisory Committee


Presenter: Katie Oswald, Executive Director
Full Spectrum Agency for Autistic Adults



1

About Katie

- Autistic self advocate
- Founder of Full Spectrum Agency for Autistic Adults
- 1,000+ members
- Peer support group leader
- Community builder
- World traveler



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Why a statewide committee?

- Nothing about us without us!
- Decisions that impact the lives of a minority group
- Solutions that address underlying cause of an issue
- Need a large, representative sample

3

Diversity in the autistic community

- Diagnostic status/age
- Support needs
- Nonspeakers/AAC users
- Intellectual disability
- LGBTQ+
- Gender
- Age
- Co-occurring conditions
- Race and/or ethnicity
- Socioeconomic
- Education level
- Geography
- Culture
- Spirituality

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Common challenges

- Unemployment or underemployment
- Poverty
- Homelessness
- Abuse, victimization, and interpersonal violence
- Loneliness and/or isolation
- Lack of mobility/transportation
- Access to healthcare and higher rates of health problems
- Severe depression, anxiety, PTSD, burnout
- Suicidality
- Reduced life expectancy

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Who should get involved in the committee

- Autistic adults
- Friends and family members of autistic people
- Disability nonprofit leaders
- Government agencies
- Policymakers
- Healthcare, education, and business communities
- Society and allies

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Committee roles and responsibilities

- 1 Survey design
- 2 Data and story collection
- 3 Communicate with peer "constituents"
- 4 Identify priorities and help design solutions
- 5 Meet monthly
- 6 Report findings
- 7 Help design committee policies and processes


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Inclusion strategies


- Primary, secondary, and multiple backup committee members
- Time off for recovery as needed
- Ability to bring aide or assistant to all meetings and activities
- Virtual participation for meetings
- Rotating in-person meeting locations
- Alternative communication accepted as equal to speech
- Other accommodations provided as requested and possible

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Next steps



Sign up for email list to stay updated



Attend a brainstorming and info session



Contact Katie with thoughts and questions at katie@FullSpectrumASD.org

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Questions/Discussion

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Sign up for email updates:



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Contact:
Katie Oswald
katie@FullSpectrumASD.org



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References

- Gibbs, V., & Pellicano, E. (2023). 'Maybe we just seem like easy targets': A qualitative analysis of autistic adults' experiences of interpersonal violence. *Autism*, 27(7), 2021-2034. <https://doi.org/10.1177/13623613221150375>
- Hymas, R., Badcock, J.C. & Milne, E. Loneliness in Autism and Its Association with Anxiety and Depression: A Systematic Review with Meta-Analyses. *Rev J Autism Dev Disord* (2022). <https://doi.org/10.1007/s40489-022-00330-w>
- Cassidy, S., Bradley, L., Shaw, R. et al. Risk markers for suicidality in autistic adults. *Molecular Autism* 9, 42 (2018). <https://doi.org/10.1186/s13229-018-0226-4>

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References

- Wilson, N. et al. Exploring the relationship between community mobility and quality of life, employment and completing further education for autistic adults. *Journal of Transport & Health*, Volume 22, 2021. <https://doi.org/10.1016/j.jth.2021.101117>
- Smith DaWalt, L., Hong, J., Greenberg, J. S., & Mailick, M. R. (2019). Mortality in individuals with autism spectrum disorder: Predictors over a 20-year period. *Autism*, 23(7), 1732-1739. <https://doi.org/10.1177/1362361319827412>
- Black, M. et al. Multi-informant International Perspectives on the Facilitators and Barriers to Employment for Autistic Adults. *Autism Research* 13: 1195-1214, 2020.

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References

- Raymaker, D. et al. "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout. *Autism in Adulthood*, Volume 2, Number 2, 2020.
- Oswald, K. Lived experience of autism.
- Full Spectrum Agency for Autistic Adults. Anecdotes from hundreds of autistic adults over the past five years.

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Unemployment

- 90% unemployment rate
- 12 months vs 22 weeks to get a job
- 24 months vs 49 months on the job
- Autistic work ethic: 90%-140% higher productivity
- Uneven social demands /constant social discrimination
- Burnout and trauma
- Most requested accommodations – part time hours, written instructions, decompression time, social reciprocity

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Autistic burnout

- Result of cumulative life stressors with barriers to support that create an inability to obtain relief
- Expectations outweigh abilities
- Negative impacts on their health and quality of life, including suicidal behavior
- 3+ months
- Acceptance and social support, time off/reduced expectations, and doing things in an autistic way/unmasking

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Suicidality

- 72% of autistic adults scored above the recommended cut-off for suicide risk compared with 33% of the general population.
- Population study showed that autistic people were significantly more likely to die by suicide (0.31%) compared to the general population (0.04%)
- Masking/camouflaging and unmet support needs increase risk of suicidality.

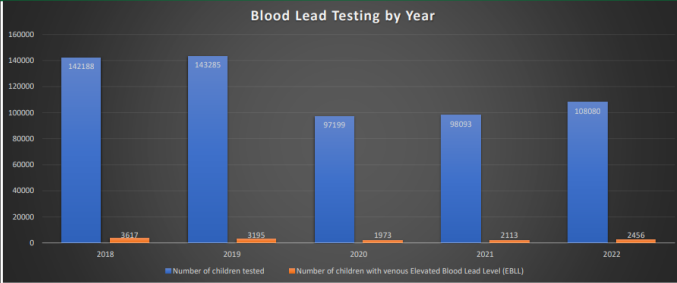
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Appendix IV

Exploring Interventions to Decrease Lead Exposure in Children with Autism and Pica

<p style="text-align: center;">Exploring Interventions to Decrease Lead Exposure in Children with Autism and Pica</p> <p style="text-align: center;">Childhood Lead Poisoning Prevention Program (CLPPP)</p> 	<p style="text-align: right;">Objectives </p> <ul style="list-style-type: none"> • Raise awareness of the lead poisoning risks for children with pica behaviors • Discuss case data and observations by CLPPP nurse consultants related to autism and pica behaviors • Identify potential collaboration opportunities between CLPPP nurse consultants and the Autism Council
<p>MDHHS – Childhood Lead Poisoning Prevention Program </p> <ul style="list-style-type: none"> • CLPPP Areas of Focus: <ul style="list-style-type: none"> • Surveillance • Education and Outreach • Nursing Case Management and Blood Lead Testing 	<p style="text-align: center;">Nursing Case Management</p> 
<p>Local Nursing Case Management Eligibility </p> <ul style="list-style-type: none"> • Offered to all children under the age of 6 years old with a venous blood lead level of $\geq 3.5 \mu\text{g/dL}$ • Focus on children under the age of 6 years old because of: <ul style="list-style-type: none"> • Exposure • Absorption • Susceptibility 	<p>Local Nursing Case Management </p> <ul style="list-style-type: none"> • Education • Physical Assessment <ul style="list-style-type: none"> • Brain and nervous system damage • Decreased IQ • Learning difficulties • Speech, language, and behavior problems • Environmental Assessment • Linkage to Resources
<p>Local Nursing Case Management </p> <ul style="list-style-type: none"> • Facilitate future blood lead testing and follow-up • Ensure referral completion • Ensure exposure sources are identified and resolved 	<p style="text-align: center;">Data</p> 

Blood Lead Testing Data



Source: <https://mitracking.state.mi.us/>

Chelation Therapy



- Indicated when BLL is 45 µg/dL or greater
 - Detroit Children's Hospital chelates at 40 µg/dL or greater
- Used for neuroprotection, not a cure for lead poisoning

Oral

- 21 days
- Outpatient
- Lead-safe environment
- Tastes and smells bad

IV and/or IM injections

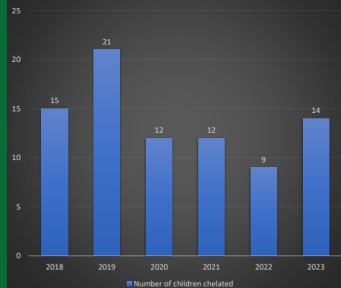
- 5 days
- Inpatient
- IM injections are painful
- Challenging to maintain IV access

High Burden of Chelation

Chelation and limited support causes trauma in these families

High financial burden to families, healthcare system, and lead services

Children that received chelation



What prompted us to explore autism and pica?



- In FY 23, anecdotally, we noticed autism and pica as a common diagnosis of our chelation cases
 - Higher incidence of autism and pica with repeat chelation cases
- Noted challenges with families having access to diagnostic and treatment providers
 - Lack of primary care provider
 - Barriers related to SDoH that hindered referral completion

Data Keywords



- Manual narrative note extraction using keywords:
 - Autism
 - Pica
 - If over the age of 24 months:
 - "Non-food"
 - "Soil" and "Eating"
 - "Paint chips" and "Eating"
 - OR positive abdominal x-ray

Source: <https://www.nationaleatingdisorders.org/pica/>

Pica Data



- Avon Longitudinal Study of Parents and Children found 2.3% of parents reported pica behaviors in their child at age 36 months and became less common as children aged
- About 7% of children that received case management had documented pica behaviors in HHLPSS, Fiscal Years 2018-2023
- 9% of children with documented pica behaviors in HHLPSS required chelation therapy, compared to 1% of children without pica behaviors, Fiscal Years 2018-2023
- 65% of children that required more than one episode of chelation therapy had documented pica behaviors in HHLPSS, Fiscal Years 2018-2023

Sources: Papini, M., Bulik, C., Chawner, S., & Micali, N. (2023). Prevalence and recurrence of pica behaviors in early childhood within the ALSPAC birth cohort. *International Journal of Eating Disorders*. <https://doi.org/10.1002/eat.24111>

Healthy Homes Lead Poisoning Surveillance System (HHLPSS) chart reviews.

<https://mitracking.state.mi.us/>, data retrieved 2/13/2024.

Putting it together, a case review



- Case child
 - Initial blood lead test > 45 µg/dL
 - Initial blood lead test performed at 23 months
 - History of autism and "severe" pica
 - Received 3 rounds of chelation therapy
 - Hospitalized 4 times
 - PICC line inserted for chelation treatment due to difficulty with keeping IV line in for treatment
 - Relocated to hotel for 14 months (intermittently)
 - Primary residence remediated twice
 - Secondary location remediated
 - ABA therapy initiated 18 months after initial blood lead test

Requested Guidance from the Autism Council

Immediate needs and future collaboration

- Interventions for pica behaviors that could be implemented by nurse case managers or the family
- Is there a way to expedite the autism assessment referral pathway
- Alternative treatment paths for pica outside of traditional autism assessment and treatment
- Ongoing communication and potential collaboration

Contact Information



- Aimee Surma, CLPPP Nurse Consultant surmaa@michigan.gov
- Julie Fox, CLPPP Nurse Consultant foxj17@michigan.gov
- Wendy Snyder, CLPPP Nurse Consultant snyderw3@michigan.gov
- Annette Gilmer, MD, Senior PH Physician gilmera1@Michigan.gov