



# Local Health Department (LHD) Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN)

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# **Table of Contents**

EXECUTIVE SUMMARY	3
INTRODUCTION	
METHODOLOGY (IES)	8
Survey Format	
Survey Distribution	
Response Rate	
FINDINGS	9
LHD-HCT Activities Assessment Survey Responses & Calculations	
Free Text Responses: Themes, Challenges and Opportunities	
THEME 1: Staffing	
THEME 2: Website Development	
THEME 3: Informational Materials	
THEME 4: Policy/Process/Procedure	
THEME 5: Client/Family Survey	
THEME 6: Documentation/Tracking Progress	
THEME 7: Staff Training	
THEME 8: Communication with Clients/Families	
THEME 9: Internal/External Partner Opportunities	21
DISCUSSION / OVERALL SUMMARY OF FINDINGS	21
Summary of 2023 CSHCS LHD Activities	
SURVEY FOLLOW UP / RECOMMENDATIONS	22
REFERENCES	23
APPENDICES	24
A: LHD-HCT Survey Distribution List	
B: 2023 LHD-HCT Assessment Survey Tool	
C: 2023 LHD-HCT Survey Link email	
D: 2023 LHD-HCT Survey Assessment Summary Report	
E: 2023 LHD Specific-HCT Survey Assessment Summary Report	
F: Monthly Transition Updates Report	
G: THD-HCT Survey Reminders	24



#### EXECUTIVE SUMMARY

The Michigan Department of Health and Human Services (MDHHS) Children's Special Health Care Services (CSHCS) program strives to enable individuals with special health care needs to have improved health outcomes and an enhanced quality of life through the appropriate use of the CSHCS system of care. A critical component of the CSHCS program is to provide Health Care Transition (HCT) guidance and support to youth and families. In Michigan, 26.2% of Children and Youth with Special Health Care Needs (CYSHCN) reported receiving services to assist with their transition to adult health care (National Survey of Children's Health, 2021-2022). While Michigan performs better than the national average, the data indicates that more than two-thirds of Michigan's CYSHCN are not receiving necessary HCT services, making them vulnerable to worsening chronic health conditions, behavioral health issues and underutilization of needed health care services.

In 2022 Michigan's CSHCS Program, in collaboration with staff from Got Transition®, developed an annual HCT assessment survey based on the Six Core Elements of Health Care Transition™. Local Health Departments (LHDs) across the State participated in the first annual HCT assessment in 2022. The goal of this first annual 2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN) survey was to establish baseline HCT data; the Survey was again administered in 2023 and the data compared to that obtained the prior year. Data will continue to be tracked annually to identify trends and enhance CSHCS-HCT program development. The Michigan State University Institute for Health Policy (MSU-IHP) provides technical assistance and support for this HCT assessment survey project.

In September 2023, Michigan's forty-five LHDs (Appendix A) were sent a link to the *Local Health Department (LHD) Assessment of Health Care Transition (HCT) Activities* tool (Appendix B) via email (Appendix C); all 45 LHDs responded to the survey (100%). Each question on the survey provided four (4) possible response levels: Level 1 (basic) through Level 4 (comprehensive). Questions addressed the following elements of HCT:

- 1. Availability of or adherence to a HCT Policy
- 2. Tracking and Monitoring HCT Activities
- 3. Availability or Use of Transition Readiness Assessment Tools
- 4. Transition Planning
- 5. Transfer of Care to Adult Providers



### 6. Evaluation of Transition Completion for Clients of Transition Completion Age

The survey also invited respondents to share suggestions or challenges they experienced related to CSHCS transition policies, documents, and trainings.

Although changes were observed in LHD responses from 2022 to 2023, these changes were not found to be statistically significant, and should not be interpreted as such. Comparative results from the 2022 and 2023 *Local Health Department (LHD)*Assessment of Health Care Transition (HCT) Activities surveys indicate:

- 49% of LHDs (N=22) showed improvement in their overall scores in 2023 when compared with 2022 survey results.
- 35% of LHDs (N=16) returned lower scores, overall, in 2023 when compared with their 2022 survey results.
- 15% of LHDs (N=7) returned scores that did not change from 2022 to 2023 survey years.
- Level 1 responses to all six survey questions decreased by 5% and Level 3 responses decreased by 2%.
- Level 2 and Level 4 responses to all six survey questions showed increases of 5% and 1%, respectively.

Most free-text comments received in 2023 mirrored concerns expressed in the 2022 survey and were related to:

- Staffing, staff HCT training and materials, and the desire to resume regional LHD meetings,
- Website improvements,
- Informational materials for staff, and the need for uniformity and consistency in following transition policies and processes, and,
- Improving transition coordinator tools, including development of an electronic plan of care and a mechanism to track progress/completion of the six core elements of HCT.

LHDs also shared that communication with clients remains a challenge, and families have expressed dissatisfaction with the frequency of outreach by the LHD. The lack of a mechanism to formally elicit feedback from clients and caregivers about LHD transition services was also identified. Often, outreach telephone calls are not returned, or forms are



not completed and mailed back as requested. One LHD observed that families have many demands on their time making scheduling an in-person transition care coordination interview with staff challenging; successful outreach (telephonic or written) with college-aged clients is often difficult as well. Person-centered client, family and caregiver transition guidance and educational materials are often provided only in hard copy. Many of the communication materials are not well suited to the needs of clients and caregivers who will require guardianship throughout their lives.

CSHCS leadership uses results from this annual survey to guide LHD support efforts by: (1) identifying opportunities to engage and interface with LHDs, (2) collaborating with LHD staff to develop additional tools and educational opportunities to guide HCT activities at the LHDs, and (3) conducting the LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN) survey annually and using the information obtained to track improvement in LHD HCT levels of activity over time.

The following reports were prepared and made available to the CSHCS leadership team and to the forty-five individual LHDs.

- 1. MDHHS 2023 Local Health Department Health Care Transition Activities Assessment Aggregate Summary, which provides a brief overview of 2023 aggregate Survey findings compared with those obtained in 2022. (Appendix D).
- 2. 2023 Local Health Department Health Care Transition Activities Assessment LHD-Specific Summary (Appendix E) which provides a graphic depiction of the individual LHD's reported level of activity for each of the core elements as well as a comparison with the average score reported, overall, for each question. In the interest of preserving confidentiality, these reports are identified by randomly assigned number instead of the name of the LHD. A Randomization KEY was provided to the CSHCS Leadership team.

The results of the 2023 Local Health Department (LHD) Care Coordination Program Assessment of Health Care Transition (HCT Activities for Youth with Special Health Care Needs (YSHCN) Final Report are available on the MDHHS website at <a href="https://www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood/health-care-teams">www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood/health-care-teams</a>.



## INTRODUCTION

According to a 2020 review of nineteen articles<sup>1</sup> published in nationally recognized healthcare professional journals, "a structured HCT process for youth with special health care needs can show improvements in adherence to care, disease-specific measures, quality of life, self-care skills, satisfaction with care, health care utilization, and HCT process of care." Since 2018, the National Survey of Children's Heath has included questions related to health care transition, and 2022 survey results show that 28% of children in Michigan who have special health care needs receive services related to health care transition compared with 23% reported nationally. This reflects a 4.4% increase over 2021 Michigan-specific results (23.6%) compared with a 2.2% increase nationally (20.8%). The survey also showed that Michigan's 21.7% response surpassed the national rate of 16.6% among those children who do not have special health care needs, also showing a 3.8% improvement over 2021 results (23.6%) compared with a 0.8% improvement nationally (15.8%).

CSHCS is committed to enabling those with special health care needs to experience improved health outcomes and enhanced quality of life through appropriate use of the CSHCS system of care. Furthermore, CSHCS views the efforts of Michigan's forty-five local public health departments to provide guidance and support to youth and their families at every stage of transition to be a critical component of this commitment. These services better prepare young, independent adults to gradually assume responsibility for their own health care decisions.

## Summary of 2023 CSHCS LHD HCT Activities

In July 2023, comments and suggestions received from the 2022 CSHCS LHD HCT Survey were reviewed and addressed through the collaborative efforts of the LHDs staff and the CSHCS HCT leadership team. Topics included the recommended age at which to begin the HCT process and reviewing, updating, or developing age-specific HCT documents and resources for the LHDs and clients. In 2023, the results of this collaborative effort were presented by the leadership team to all LHDs (Appendix F) and was used as a catalyst for continuing HCT education and discussion:

<sup>&</sup>lt;sup>1</sup> Databases included CINAHL, OVID Medline, PubMed, Scopus, Web of Science <sup>2</sup> Annie Schmidt, Samhita M. Ilango, Margaret A. McManus, Katherine K. Rogers, Patience H. White, Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review, Journal of Pediatric Nursing, Volume 51, 2020, Pages 92-107, ISSN 0882-5963, <a href="https://doi.org/10.1016/j.pedn.2020.01.002">https://doi.org/10.1016/j.pedn.2020.01.002</a>.



- The recommendation to begin HCT at age 12 years was reaffirmed to provide adequate time for the child to learn how to take an active role in their medical care, build advocacy skills, expand their knowledge of the complex medical system, increase independence with self-care and prepare for an adult model of health care.
- Updated or newly developed documents included:
  - o The Six Core Elements of HCT A Quick Guide for LHDs,
  - o Transition Checklist for LHDs,
  - o Sample Transition Policy,
  - o College and CSHCS,
  - Transition Planning Guidebook for Youth and Families
- All Transition to Adulthood documents, including client/family communications
  were reviewed, updated and made available at
  <a href="https://www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood">https://www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood</a>.
- The *Transition Report*, which is sent out to all LHDs each month, was revised to include all transition aged clients (ages 12 to 21 years.)

Adulthood/LHD Transition Resource Manual.pdf?rev=87d2ac9ebcd1462ba48c b1871b6e0ff0&hash=B079E234A629349D9D4AF8B1E23CB87C.

Also in 2023, the CSHCS leadership team renewed their commitment to help streamline the transition process, continued to offer guidance and support to their LHD partners, and measure improvement in meeting the Six Core Elements of Health Care Transition through the annual CSHCS LHD HCT Survey process.



# METHODOLOGY (IES)

#### **Survey Format**

The electronic survey was formatted using the Qualtrics® online survey platform and was comprised of six (6) multiple choice and one (1) free-text response questions. (Appendix B).

The multiple-choice questions were based on those found in the original The Six Core Elements of Health Care Transition<sup>TM</sup> survey tool and, with the permission of the Got Transition® staff, were modified by the CSHCS-HCT team. For each multiple-choice question, responding LHDs were asked to select the level of activity which best described their own activity regarding key components of the health care transition process, Level 1 being the most basic, and Level 4, the most comprehensive.

The six questions explored activities related to the following HCT components:

- 1. CSHCS Transition Policy
- 2. CSHCS HCT Tracking and Monitoring
- 3. Transition Readiness Assessment Tools
- 4. Transition Planning
- 5. Transfer of Care
- 6. Transition Completion

Using a free text format, respondents were also given the opportunity to share any suggestions or challenges they may have encountered regarding CSHCS transition policies, documents, and trainings.

# **Survey Distribution**

In October 2023, MDHHS-CSHCS leadership emailed forty-five previously identified key staff members at each of Michigan's local health departments, asking them to complete the 2023 LHD-CC Program Assessment of Health Care Transition Activities for YSHCN survey electronically, using the Qualtrics® online survey platform. The survey tool was accompanied by an introductory email (Appendix C). In some cases, two or more local health departments manage CSHCS activities from the same location. For these LHDs, only one survey response was elicited. It was recommended that survey respondents



discuss and complete the assessment with their respective CSHCS care coordination team prior to preparing their response.

#### Response Rate

The survey link remained open for 21 days prior to closing. Four (4) reminders (Appendix G) to complete the survey were sent by email at regular intervals throughout the survey period. Survey respondents did not report difficulties accessing or completing the survey. Forty-five (45) LHD staff received the link to complete the 2023 LHD-CC Program Assessment of Health Care Transition Activities for YSHCN survey on-line and all 45 LHD staff responded, resulting in a 100% survey completion rate. All 45 LHDs responded to each of the six (6) multiple choice questions and 35 LHDs (78%) offered free text comments compared with 39 (89%, N=45) in the 2022 survey.

#### **FINDINGS**

#### LHD-HCT Activities Assessment Survey Responses & Calculations

In October 2023, the State of Michigan Children's Special Health Care Services (CSHCS) program conducted the second annual survey of all LHDs regarding their Transition to Adulthood activities and the implementation of the Six Core Elements of Health Care Transition (HCT). This survey assessment obtained 2023 data related to each LHD's current HCT activities to be compared with baseline data obtained in 2022. Paired t-tests were conducted for all the questions ( $\alpha$  = 0.05, two-tailed) for LHDs that responded in both years and there were no statistically significant changes in mean responses between 2022 and 2023 for any question.

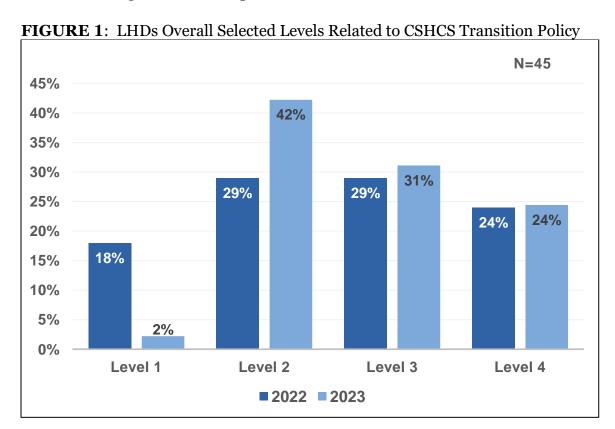
The following section summarizes the LHD's responses to questions about their activities related to transition policy, tracking and monitoring transition activities, transition-readiness assessment tools, transition planning, transfer of care to adult providers and HCT program evaluation. A summary of free-text comments and suggestions is also provided.

Each of the survey's six (6) multiple choice questions, and the possible responses, appear below. For each question, the respective activities characteristic of response Levels one (1) through four (4) are progressively more robust, culminating in the most comprehensive approach to HCT activities, e.g., Level 4. The figure below each question shows the percent of LHDs selecting each level, respectively.



**Question 1:** Please select the level that would best describe your LHD's CSHCS Transition Policy.

- **Level 1.** Care coordinators follow a similar approach to HCT but do not have a written policy.
- Level 2. The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends.
- **Level 3.** The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends. Care coordinators consistently discuss HCT with all YSHCN and their families, beginning at ages 12 to 14.
- Level 4: The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends. Care coordinators consistently discuss HCT with all YSHCN and their families, beginning at ages 12 to 14. The transition policy also describes the facilitation of additional transition to adulthood domains including work and independence.



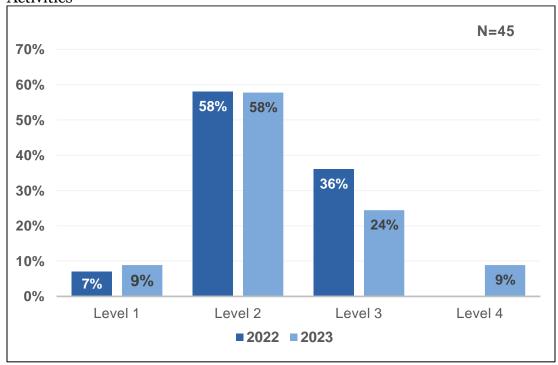


In 2023, when asked to select what best described their CSHCS Transition Policy, LHDs showed a desireable 16% drop in Level 1 responses, and appreciated a similar gain in Level 2 responses (13%). Level 3 responses showed only a 2% gain and Level 4 responses remained unchanged. It is worth noting that Level 1 activity shifted to higher levels, overall, and Level 4 activity did not decrease from 2022 to 2023.

**Question 2:** Please select the level that would best describe your LHD's CSHCS HCT Tracking and Monitoring.

- **Level 1.** Care coordinators vary in the identification of transition aged YSHCN, but most wait until close to the age of transfer to prepare youth for HCT.
- **Level 2.** Care coordinators use client records to document relevant HCT information (ex: discussed transition, date of transfer to adult doctor).
- **Level 3.** The care coordination program uses an individual transition tracking system for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some but not all the Six Core Elements of HCT.
- **Level 4.** The care coordination program uses an individual transition tracking system for identifying and tracking all transition aged YSHCN, ages 14 and older as they complete all the Six Core Elements of HCT.

**FIGURE 2:** LHDs Overall Selected Levels Related to Tracking and Monitoring HCT Activities



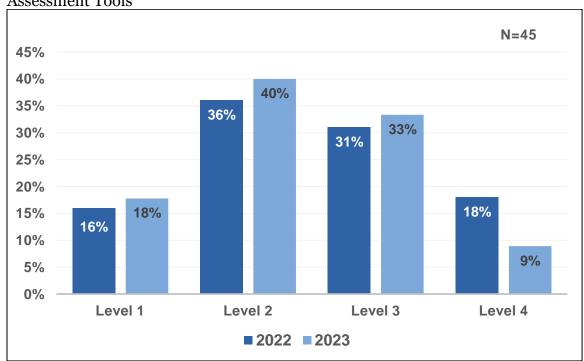


The majority of LHDs (58%) reported their activity related to Tracking and Monitoring at Level 2, both in 2022 and 2023. Although there was a slight increase in Level 1 activity (2%), a 12% decrease in Level 3 activity reported, accompanied by a 9% gain in Level 4 activity indicates overall improvement.

**Question 3:** Please select the level that would best describe your LHD's CSHCS Transition Readiness assessment tools used in identifying the needs of YSHCN and their families.

- Level 1. Care coordinators vary in whether they assess HCT readiness/self-care skills.
- Level 2. Care coordinators assess HCT readiness/self-care skills but do not consistently use a HCT readiness assessment tool.
- Level 3. Care coordinators assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.
- **Level 4:** Care coordinators consistently assess and re-assess each year HCT readiness/self-care skills, starting at ages 14 to 16, using a transition readiness/self-care assessment tool.

**FIGURE 3:** LHDs Overall Selected Levels Related to Transition Readiness Assessment Tools





LHDs responses related to the use of readiness assessment tools among care coordinators showed slight increases in Level 2 (4%) and Level 3 (2%) activity, however, these improvements are offset by a 9% decrease in Level 4 activity and a 2% increase in Level 1 activity. Care must be taken not to interpret these shifts as indicitive of a downword trend, however, it does indicate an area on which LHDs could focus further quality improvement efforts.

**Question 4.** Please select the level that would best describe your LHD's CSHCS Transition Planning.

- **Level 1.** Care coordinators vary in whether they include goals and action steps related to HCT in the plan of care for YSHCN.
- Level 2. Care coordinators consistently include goals and action steps related to HCT for YSHCN but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused healthcare.
- Level 3. Care coordinators consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness assessment tool. Care Coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. The plan of care is regularly updated.
- Level 4. The care coordinator program has incorporated HCT into its plan of care template for all YSHCN. Care coordinators consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness assessment tool. Care coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. The plan of care is regularly updated and shared with YSHCN and families.

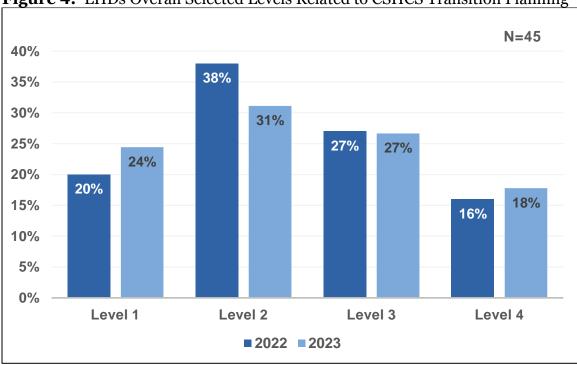


Figure 4: LHDs Overall Selected Levels Related to CSHCS Transition Planning

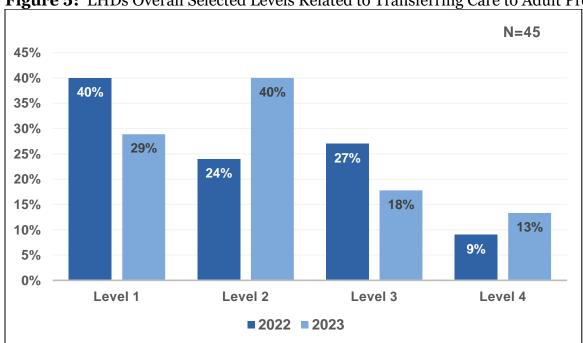
Including goals and action steps in the transition plan, addressing privacy and consent changes that occur at age 18, and identifying decision-making supports if needed are critical components of transition care planning. In 2023, LHDs appreciated a 2% gain in reported Level 4 activity, while Level 3 activity remained constant at 27%. Level 2 activity decreased by 7% in 2023, and Level 1 activity reflected a 4% increase in LHDs reporting the lowest activity level for this question.

# Question 5. Please select the level that would best describe your LHD's activities related to Transfer of Care to adult providers for CSHCS clients.

- **Level 1.** Care coordinators vary in whether they provide YSHCN and families with resources to find adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.
- Level 2. Care coordinators consistently provide YSHCN and families with resources to find adult providers and share plans of care with HCT information to adult providers for their transitioning YSHCN. Care coordinators vary in whether they include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN.
- Level 3. Care coordinators consistently provide YSHCN and families with resources to find adult providers and share plans of care with HCT information to



- adult providers for their transitioning YSHCN. Care coordinators include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN.
- Level 4. Care coordinators consistently provide YSHCN and families with resources to find adult providers and share the plan of care with HCT information to adult providers for their transitioning YSHCN. Care coordinators include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN. In addition, care coordinators routinely communicate with the youth or family that transfer of care to adult providers was completed.



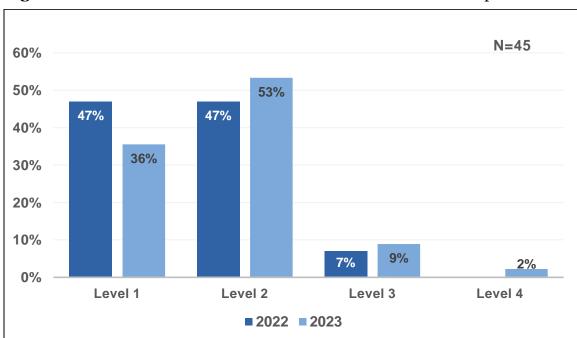
**Figure 5:** LHDs Overall Selected Levels Related to Transferring Care to Adult Providers

One of the most difficult challenges facing parents and caregivers is identifying appropriate primary care and specialty care providers for their young adult children. CSHCS care coordinators can be instrumental in assisting in this process by providing families with the names and contact information of adult providers who can meet the needs of the transitioning youth as well sharing the current plan of care with the receiving practitioner. Although the data is insufficient to calculate the statistical significance of these changes, an 11% decrease in Level 1 responses and a 16% increase in Level 2 responses were observed. From 2022 to 2023, the 7% drop in reported Level 3 activity is accompanied by a 5% increase in Level 4 activity.



**Question 6.** Please select the level that would best describe your LHD's activities regarding HCT program evaluations for CSHCS clients that are of <u>Transition Completion</u> age.

- Level 1. Care coordinators vary in whether they follow-up with YSHCN and parents/caregivers about the HCT support provided by the care coordinator program.
- **Level 2.** Care coordinators consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey.
- **Level 3.** Care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey.
- **Level 4.** Care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey and use the results as part of its transition performance measurement for the Title V block grant reporting.



**Figure 6:** LHDs Overall Selected Levels Related to Transition Completion

In 2022, the majority of LHDs reported Level 1 or Level 2 activity related to obtaining comments and suggestions from YSHCN parents and caregivers, 47% and 47%, respectively. Again, in 2023, the majority also reported Level 1 or Level 2 activity for this question, however Level 1 activity dropped 11% (from 47% to 36%) while Level 2 activity



rose by 6% (from 47% to 53%). Two percent (2%) gains were also seen in Level 3 and Level 4 responses. Over all gains in Levels 2, 3, and 4 are encouraging with respect to improving consistency among LHD's post transition evaluation efforts.

#### Calculations and Methods

Figures 7 and 8 (below) shows the percentage of LHDs selecting Levels 1, 2, 3, and 4, respectively, in response to each of the questions related to the Six Core Elements. The percentage for each level was calculated using the number of LHDs who responded to each level, (x), divided by the total number of respondents (x/45). For example, if nine (9) LHDs selected Level 1 in response to a particular question, 9/45 = 20%. Note that in 2022, none of the 45 LHDs selected Level 4 when responding to Question 2 or Question 6.

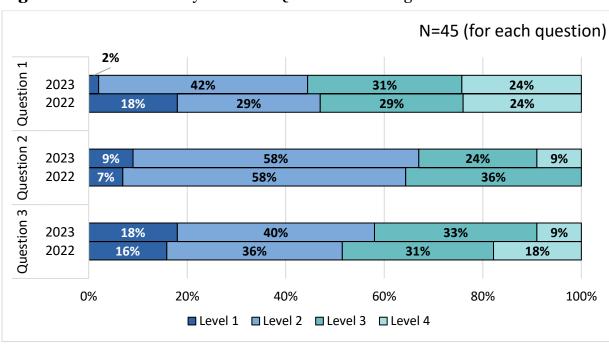
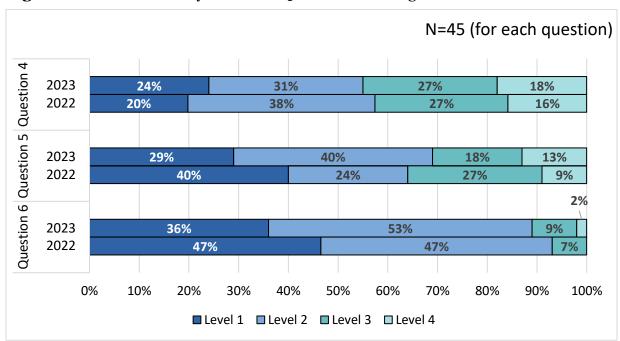


Figure 7: Selected Activity Levels for Questions 1 through 3



**Figure 8:** Selected Activity Levels for Questions 4 through 6

Further calculations were performed to determine the difference in the percent of LHDs response Levels, from 2022 to 2023, for Questions 1 through 6, overall. (Figure 8). From 2022 to 2023, Level 1 responses decreased overall by five percent (5%), whereas Level 2 responses increased 5.34%. For the same period, Level 3 responses decreased by 2% and Level 4 responses increased by 1.34% overall. Gains made in the percentages of Level 2 and Level 4 responses are encouraging, however, caution should be exercised in interpreting these changes considering the lack of statistical significance.

Figure 9: Difference in Percentage of LHD Responses, by Level, 2022 to 2023

	Level 1		Level 2		Level 3		Level 4	
	2022	2023	2022	2023	2022	2023	2022	2023
Q 1	18%	2%	29%	42%	29%	31%	24%	24%
Q 2	7%	9%	58%	58%	36%	24%	0	9%
Q 3	16%	18%	36%	40%	31%	33%	18%	9%
Q 4	20%	24%	38%	31%	27%	27%	16%	18%
Q 5	40%	29%	24%	40%	27%	18%	9%	13%
Q 6	47%	36%	47%	53%	7%	9%	0	2%
Total/6	148%/6	118%/6	232%/6	264%/6	157%/6	142%/6	67%/6	75%/6
	(24.66%)	(19.66%)	(38.66%)	(44.00%)	(26.16%)	(23.66%)	(11.16%)	(12.5%)
Change	5%*		5.34%**		2%*		1.34%**	

<sup>\*</sup>RED font indicates a decrease in the overall percentage of LHDs responding at the given Level.

<sup>\*\*</sup>GREEN font indicates an increase in the overall percentage of LHDs responding at the given Level.



#### Free Text Responses: Themes, Challenges and Opportunities

When LHDs were asked to share any suggestions or challenges they may have related to CSHCS transition policies, documents, and trainings, 78% (N=35) provided free-text responses compared with 86% (n=39) in 2022. These responses are summarized according to theme, and opportunities for program development and improvement are also identified.

#### THEME 1: Staffing

- Challenges: Less than optimal staffing levels due to turnover or temporary re-assignment of CSHCS staff to work in other areas. Newly hired staff need time to develop efficiency.
- Opportunities: Whenever possible, minimize the need to re-assign CSHCS staff to other areas. Review current staff orientation process to identify areas for improvement.

#### THEME 2: Website Development

- Challenges: MDHHS health care transition site (web page) is not user-friendly; the Health Care Transition Plan of Care (HCT-POC) is not available on the forms link.
- Opportunities: Review and revise the current MDHHS health care transition web page(es) to improve the user experience and gain efficiency; review contents of the forms link, add forms such as the HCT-POC and others, revise or delete outdated or obsolete forms.

## **THEME 3: Informational Materials**

- Challenges: In some cases, informational materials for families are available in hard-copy only; some informational materials are not suitable for use with cognitively impaired youth of transition age or those who will be in guardianship in adulthood; lack a single, comprehensive resource for clients/families about the transition process.
- Opportunities: Provide print-on-demand client/family informational materials, forms and documents that can be customized depending on the needs or circumstances of the client/family. Consider making some materials accessible to families on the CSHCS website. Consider creating a



transition workbook for clients/families to guide them through the HCT process as their child matures; include articles about HCT in the CSHCS client/family newsletter.

#### THEME 4: Policy/Process/Procedure

- Challenges: Clients/families frequently do not complete/return forms necessary to update the Plan of Care (POC); the POC is not available electronically; lack of standardized policies/procedures for all LHDs; some policies/procedures are outdated.
- Opportunities: Examine reasons why clients/families do not complete/return forms, consider postage-paid return envelopes if not already in use and possible incentives that could be provided; appoint a workgroup to review, revise, update, standardize current policies/procedures and develop a plan for distribution to all LHDs; develop transition materials suitable for use with clients/families who are of transition age but likely will not reach adulthood due to their condition.

#### THEME 5: Client/Family Survey

- Challenge: Currently there is no consistent mechanism to elicit feedback from clients/families about HCT services provided by CSHCS/LHDs.
- Opportunity: Consider incorporating questions about HCT in the current annual survey or develop a separate, annual HCT survey tool.

#### THEME 6: Documentation/Tracking Progress

- Challenge: Currently there is not a method to easily track progress/completion of the six core elements of HCT.
- Opportunity: Develop a mechanism to track stages and completion of elements throughout HCT continuum, such as an electronic, searchable database to assist with tasks lists, creating age-specific lists of clients in need of transition services, and creating reports.

#### THEME 7: Staff Training

• Challenges: Lack of a standardized HCT transition training materials for staff; need for more frequent discussion of challenges related to HCT.



 Opportunities: Develop a standard process and HCT training materials and for current and newly hired staff, including a video containing examples of best practices; include HCT discussion at all staff meetings.

#### THEME 8: Communication with Clients/Families

- Challenges: Clients/families often do not return phone calls or respond to letters or other materials sent to them; families have expressed dissatisfaction with the frequency of communication outreach by the LHD; families have many demands on their time making scheduling an inperson transition care coordination interview with staff; successful outreach (telephonic or written) with college-aged clients is often difficult.
- Opportunities: Ask the client/family to identify the "best way" or "best time" to contact them and try to adhere to the request; inform clients/families of the importance of maintaining contact throughout transition. Consider using meeting platforms such as Zoom, Skype, or Teams to meet with clients/families in cases where face-to-face meetings are difficult to hold.

THEME 9: Internal/External Partner Opportunities

- Resume regional LHD meetings.
- Consider establishing a workgroup with representatives from state-level CSHCS, regional LHDs, and Medicaid Health Plans to establish and/or revise policies and procedures related to HCT and share best practices.

# DISCUSSION / OVERALL SUMMARY OF FINDINGS

# Summary of 2023 CSHCS LHD Activities

Comments and suggestions received from the 2022 CSHCS LHD HCT Survey were reviewed and addressed through the collaborative efforts of the LHDs and the CSHCS HCT leadership team. Topics included the recommended age at which to begin the HCT process and reviewing, updating, or developing age-specific HCT documents and resources for the LHDs and clients. In 2023, the results of this collaborative effort were presented by the leadership team to all (Appendix F) and are summarized below:



- The recommendation to begin HCT at age 12 years was reaffirmed to provide adequate time for the child to learn how to take an active role in their medical care, build advocacy skills, expand their knowledge of the complex medical system, increase independence with self-care and prepare for an adult model of health care.
- Updated or newly developed documents included:
  - o The Six Core Elements of HCT A Quick Guide for LHDs,
  - o Transition Checklist for LHDs,
  - o Sample Transition Policy,
  - o College and CSHCS,
  - Transition Planning Guidebook.
- All Transition to Adulthood documents, including client/family communications
  were reviewed, updated and made available at:
   <a href="https://www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood">https://www.michigan.gov/mdhhs/assistance-programs/cshcs/transition-to-adulthood</a>.
- The *Transition Report*, which is sent out to all LHDs each month, was revised to include all transition aged clients (ages 12 to 21 years.)
- Completed the *LHD Transition Resource Manual* and made it available in pdf format as well as electronically. The manual includes comprehensive information about the Six Core Elements of Health Care Transition, transition topics and activities by age, private duty nursing considerations, health insurance considerations, and quality improvement topics. The manual is available online at: <a href="https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Assistance-Programs/Childrens-Special-Health-Care-Services/Transition-to-Adulthood/LHD\_Transition\_Resource\_Manual.pdf?rev=87d2ac9ebcd1462ba48cb1871b6e0ff0&hash=B079E234A629349D9D4AF8B1E23CB87C</a>

# SURVEY FOLLOW UP / RECOMMENDATIONS

In 2023, the CSHCS leadership team renewed its commitment to help streamline the transition process, continue to offer guidance and support to their LHD partners, and measure improvement in meeting the Six Core Elements of Health Care Transition through the CSHCS LHD HCT Survey process.



Prior to the anticipated 2024 CHSCS HCT survey, it is recommended that CSHCS leadership continue this collaboration on the following identified areas:

- Resume regional LHD meetings,
- Identify and explore staff recruitment and retention opportunities,
- Develop/revise current staff orientation materials related to HCT,
- Provide HCT staff update education at regular intervals and provide opportunities for LHDs to share best practices,
- Continue web page revisions to improve the user experience,
- Continue revision or design of transition coordinator tools and written communications targeting clients/families/caregivers; create an electronic version of the plan of care which includes a mechanism to track complete/incomplete steps in the HCT process,
- Increase awareness of internal policies and procedures related to HCT and review and revise these at regular intervals, or at least annually,
- Develop a pre and post transition client/family/caregiver survey to assess communication barriers related to method and frequency, and
- Develop conversation guides for coordinators to explain to clients/family/caregivers, the necessity of completing and returning forms.

The LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN) survey provides self-reported information about the current level of LHD activity related to the health care transition for each of Michigan's LHDs. These activities have been undertaken in an effort to improve the HCT experience for youth and families, as well as to modify and improve the tools and processes utilized by LHD staff as they facilitate HCT for the clients they serve. CSHCS and the LHD are encouraged to pursue this survey process again in 2024.

#### REFERENCES

Annie Schmidt, Samhita M. Ilango, Margaret A. McManus, Katherine K. Rogers, Patience H. White, Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review, Journal of Pediatric Nursing, Volume 51, 2020, Pages 92-107, ISSN 0882-5963, https://doi.org/10.1016/j.pedn.2020.01.002.



# **APPENDICES**

A: LHD-HCT Survey Distribution List



APPENDIX C (2023 LHD-HCT Srvy Link em

B: 2023 LHD-HCT Assessment Survey Tool



APPENDIX B (2023 LHD-HCT Assessment

C: 2023 LHD-HCT Survey Link email



APPENDIX C (2023 LHD-HCT Srvy Link em

D: 2023 LHD-HCT Survey Assessment Summary Report



APPENDIX D (2023 LHD HCT ActivAssmt 5

E: 2023 LHD Specific-HCT Survey Assessment Summary Report



APPENDIX E (2023 LHD Specific-HCT Aciv

F: Monthly Transition Updates Report



APPENDIX F (Transition Updates -I

G: LHD-HCT Survey Reminders



APPENDIX G (Survey Reminders).docx