

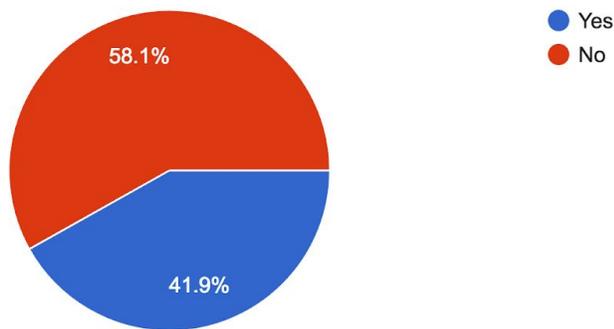
CCO/HH Participant Survey

This survey has been developed by OPWDD Family Advocates for purposes of trouble shooting any issues or concerns with the recent changes implemented in NYS on July 1, 2018. All MSCs Medicaid Service Coordinators were discontinued. Individuals with MSCs were told that they must join a CCO (Care Coordination Organization). CCOs offer two options either HCBS Basic care management or A Health Home Care Manager, We would like to continue to make our voices heard. We intend to share the results of this survey so that improvements can be made.

Survey Open From October 10th-December 3rd 2018

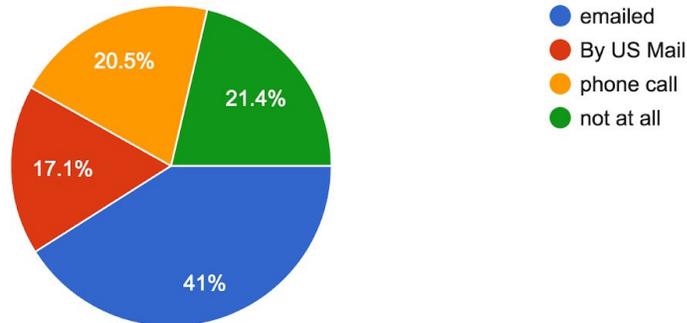
Did you understand the Care Coordination Organization /Health Home program rollout before it happened?

129 responses



How were you informed?

117 responses



What were you told?

98 responses

1. Not enough
2. just that the transition was happening, but not what it entailed
3. nothing other than the date it was taking place
4. I received the printed materials prepared by OPWDD, but help from SKIP our MDC provider was very poor
5. I was sent a flyer explaining the change over to CCO's
6. Changes made in OPWDD organization, less visits or help if I chose "Basic" over comprehensive".
7. I actually read the application and sent comments which were ignored by OPWDD.
8. need to choose basic or comprehensive by next week or won't get benefits
9. We were given info at least six months or even longer about what was taking place
10. MSc is not going to exist and
11. Attended information sessions on it through OPWDD before the turnover. I was told we'd be able to keep our MSC (hopefully) but they were just going to switch to another organization. This was to reduce the conflict of interest from services.
12. That it was happening by July 1st
13. Comprehensive description of what was coming
14. mscs were becoming care coordinators
15. That some changes were gonna be made but in the end everything was gonna stay the same
16. I don't remember any of it!

17. Since you have self direction you should choose Home health comprehensive since you would not get enough support with basic
18. A new system being rolled out.
19. Services are being centralized under CCOs to prepare for managed care
20. By my coordinator
21. Replacing MSC system. To be conflict free. More oversight on health issues.
22. M*****
23. Changing to new Care Coordination model and that my current Medicaid Service Coordinator would help with the transition
24. That the change would happen but that details would be forthcoming--that nobody knew anything, not even the supervisors knew specifics or who would be our contact people, which appears to have all been true (i.e. the the start up was a mess and nobody was told specifics).
25. I was told that my MSC would now become a Care Coordinator for Life Plan
26. I found out from GROW, the parent advocacy organization.
27. that opwdd was changing something which does nothing but make my life more difficult.
28. My msc did very little. NYS as far as I can remember sent nothing via mail or email.
29. My daughters MSC would become her Care Coordinator under a new organization. She would be the point person on all services. The roll out would be done in phases.
30. There were changes being made and instead of having msc's we wouldn't be dealing with the agency only the healthcare agency in which you will have a care coordinator
31. attended several seminars provided by DDSO and the CCOs. I was told that MSC would no longer be a service and that a similar but enhanced service would be provided by a CCo.
32. That we needed to make a change. Very little explanation
33. Not much as the MSC did not have a lot of information
34. email from skip of ny
35. "It's all changing and it's going to be a mess"
36. Whatever information OPWDD put "out there" for public consumption
37. conversation with MSC
38. That the new system would incorporate both Medical Home and Service Coordination
39. That we'd be moving toward a " more coordinated system of care"
40. was fpgiveninfo about the I/DD health home and care coordination
41. that changes were coming
42. That current MSC would explain further details
43. That MSC's would become Care Managers under the CCO's
44. I read all the stakeholder info on line i went to 3 question and answer sessions at OPWDD, FREE and QSAC
 now services would be CONFLICT FREE because the MSC/ CARE COORDIATOR would not be affiliated with an agency
 Care coordinator would be so much better than MSC
 My care coordinator is my former MSC her office is in QSAC. I heard a lot of lies about how much better things would be. I heard nothing about managed care

45. Was also informed by multiple public meetings and OPWDD policy documents. The essence was: Conflict-free Case management is coming, as the first step in a multi-year transition to Managed Care
46. It was out of My son's current(at the time) agency's control. That they were very unhappy about the change. That we needed to choose the complex/comprehensive option in order to keep the same coordinator or to have our SD work -as the basic option would not give us access to coordination service without very long wait times- months and that that would be a problem with our SD launch- felt very confusing and coercive- we were/are worried!
47. we are changing who we are working for- nothing is changing
48. That the MSC will become your Care Manager.
49. I didn't understand the changes
50. That I needed to sign some paperwork for the change to a new system but not to worry because nothing is changing. Which we all know now isn't true.
51. I was told that it would be better for me. I am not sure and what is tier 4 and why do I suddenly qualify
52. That there would be no more MSC"s and they would be replaced with care coordination which would have "life plans."
53. that managed care would be for all special needs people who receive medicaid/medicare service
54. I sought out meetings. Our Broker was essential - her help and advice was crucial
55. That the program would now include coordinating medical care.
56. We title now more MSC
57. nothing
58. That it would be full coordination if services
59. There will be a change.
60. I took the Webinar. I heard it and understood it, but that is not the reality of it and there are a lot of missing pieces.
61. Our MSC services were moving over into Care Management effective July 1, 2018 and the agency would be changing to a Care Management agency in which the Care Manager would now be reporting to.
62. Not a whole lot other than MSC's were being eliminated and CCO was taking over.
63. Basic info. Few if any details that could be confirmed.
64. I was told which one my current msc was going to be in.
65. Discussion with my MSC but he did not know very much in June
66. That we could keep our MSC who would be moving to a CCO organization
67. clarify question above-- we were informed by MANY sources: emails from OPWDD, from our MSC organization, from SANYS to name a few. There was LOTS of forums by our existing MSC agency (LIAC), OPWDD and the CCOs. We were "reassured" that this was NOT managed care, it would be "better" and that there would be few negative changes and people would transition with their MSC. Many of the power points, especially those by OPWDD were canned, and the OPWDD reps were stating party line...and often with vague or over-reassuring information. It was also clear, and stated, that there were (too) many still unanswered questions and unclear expectations. Neither OPWDD or the CCOs knew what would be happening before the deadlines: the process

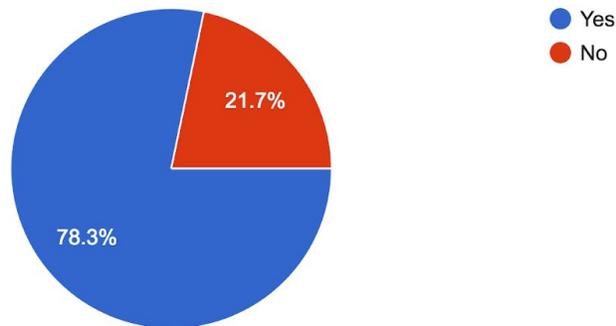
was not planned out, was rushed, and was evolving moment to moment. Both CCO and OPWDD reps stated that although they requested extensions so this would not have to roll out in June, CMS refused to allow an extension.

68. It was really for those who are not being cared for by their parents. and that I wouldn't really notice any changes.
69. medicaid coordinator during May 2018 bi- annual review advised that there was an upcoming change and handed me a colored flyer. i was then told that if i wanted to continue services i would have to sign a form and if i didnt agree to the more involoved "management" i would barely receive any assistance.
70. medicaid service coordinators would now be care coordinators
71. New change msc now cco
72. That a change was happening
73. That no one was sure of details
74. a new system was replacing MSC
75. I went to 2 forums about Jay Nagy's CCO and one run by OPWDD. I was told it was preferable to sign my son up for a Health Home Care Coordination because it was a more "robust" service. Since then, I have discovered that there is no plan in place to accommodate individuals who have private health insurance in the Home Health option. Based on what I know now, I think I probably should have signed my son up for HCBS Basic Care Management to handle his OPWDD approved services only.
76. I signed up for an information session presented by OPWDD which I learned about from an email from Parent to parent of Long island. The shift to "person centered" planning was explained as well as the change in structure to Care Coordination vs. Medicaid Service Coordination. It was very poorly explained to me by the MSC I had at the time, who then quit the agency and my son's case fell through the cracks.
77. What I learned I learned mostly from parents
78. When I asked our MSC, when I heard from other parents
79. I do not rembmer - but I was asked to sign the comprehensive plan, and when I said no, they were persistent.
80. Nothing much except it would be u Dee one umbrella
81. That it would be the same as before, but my MSC would now be called a Care Manager. I have no idea what CCO can offer me. All I know is hearsay from others. I am on my 3rd care manager since 7/1/18 (Head Injury) and none of the supervisors call back or respond to emails.
82. That it would be a better organized system. So far it is more bureaucratic, more costly to tax payers, and not improved at all for people just entering Self Direction.
83. The OPW would be forming Care coordination organizations that would replace the current system because they are trying to also coordinate health care eventually leading to Managed Care.
84. Only that the name would change.
85. As we have gone along I have gotten more information every time I have met with my care coordinator

- 86. I needed to come to the office to sign documents for care coordination and was discouraged from selecting basic and wound up getting home health care
- 87. Not sure
- 88. Our mcs
- 89. Former MSC told me, but not explanation
- 90. Not much was clear. Most good info came from special needs lists
- 91. Attended information meetings
- 92. Being moved to a different program
- 93. That the MSCs would be changed to CCOs.
- 94. in person told that an IAm assessment (no description offered) had to be done and would take hours of in-person interview
- 95. Not much just that may MSC would be transferring to care design ny but it was clear she was not given much information.
- 96. A lot of confusing information
- 97. My care coordinator
- 98. we no longer would have a medicaid service coordinator and we now should sign up with a new organization that provides care coordination. Same thing but different organization.

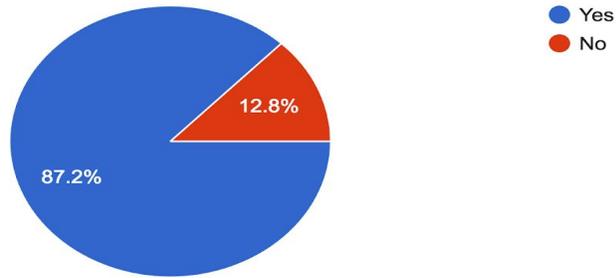
If your primary language is not English, were you given adequate information in your primary language?

46 responses



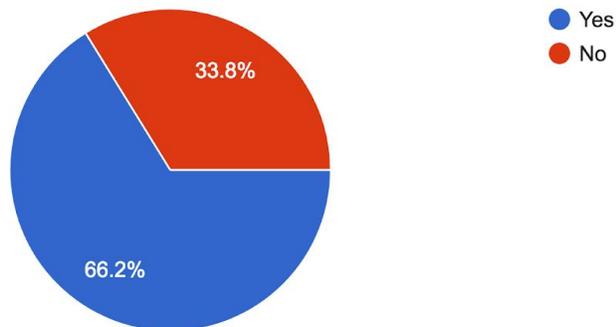
Have you been provided information about your care manager in a language you understand?

109 responses

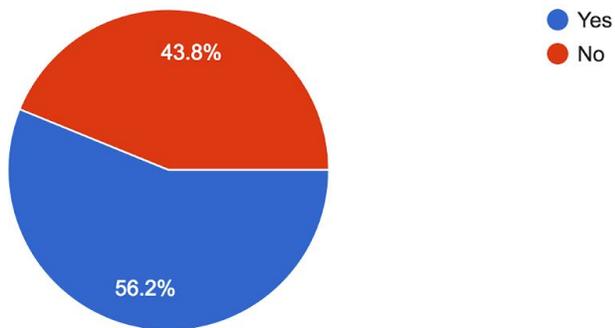


Have you ever been told anything about the Individualized Service Plan (ISP) being converted to a Life Plan (LP) from your Medicaid Service Coordinator or Care Manager ?

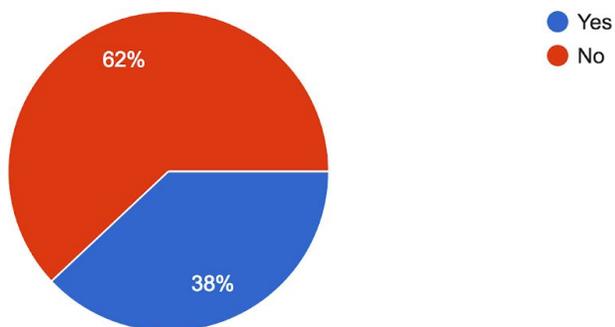
130 responses



Are you aware that the ISP will be converted to a life plan by July 2019? 130 responses

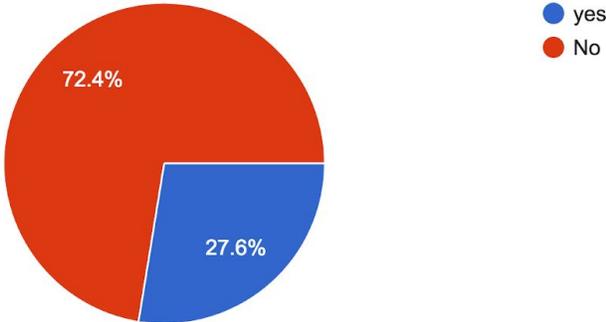


Have you ever been told anything about the "I Am assessment" from OPWDD or your CCO/HH? 129 response



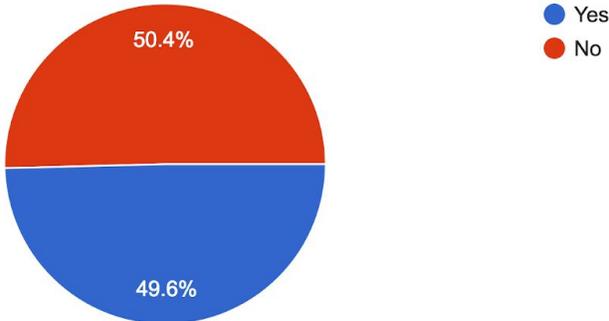
Did your MSC or Care Manager explain to you how you or your child's confidential information will be handled by the new CCO and how they will protect you or your child's privacy rights?

127 responses



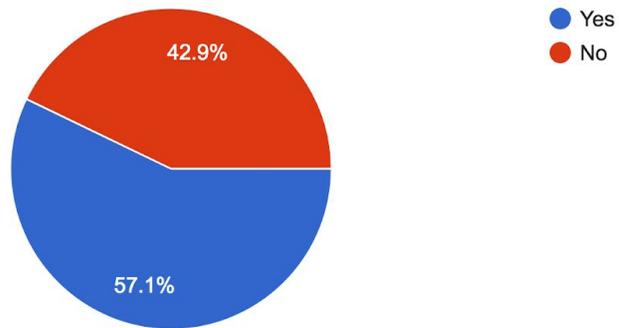
Do you have a written notice with the name of your care manager?

127 responses



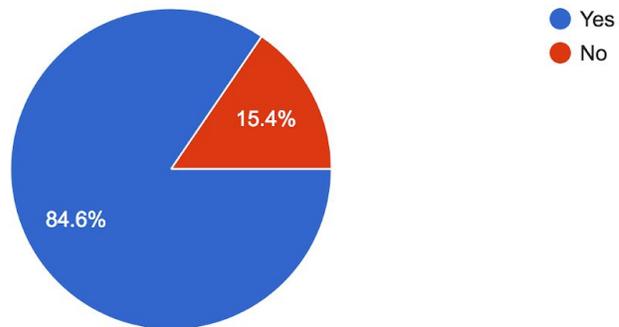
Do you know what number to call to get help?

126 responses



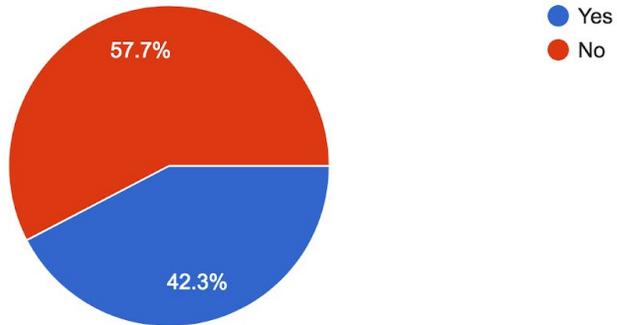
Are you enrolled in a Care Coordination Organization/ Health Home ?

123 responses



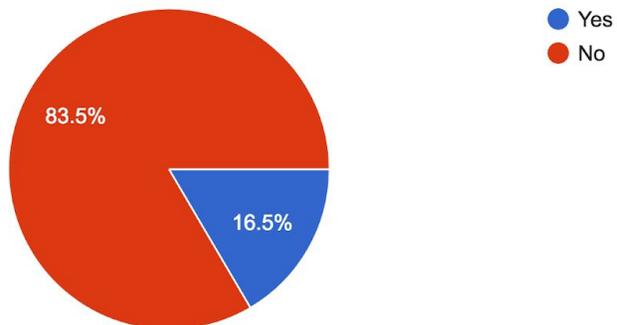
Are you enrolled in Basic HCBS Plan Support?

111 responses



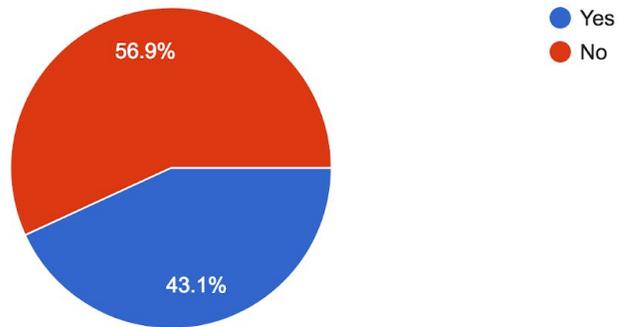
Have you completed the I AM assessment?

127 responses



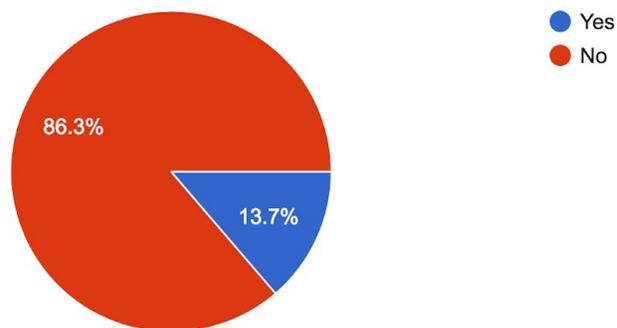
Were there any technological difficulties doing the I AM?

51 responses



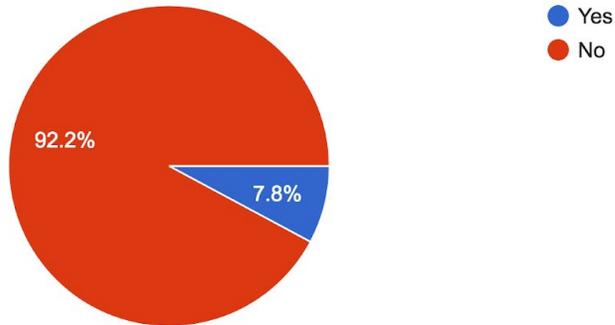
Has the Care Manager developed a Life Plan with you yet ?

124 responses



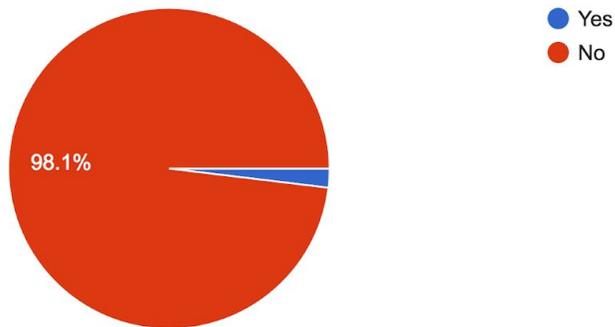
Have you lost any traditional HCBS services since 7/1/2018 ?

115 responses



Have you lost a fair hearing because you lacked Care Manager or Service Coordinator representation?

105 responses



What if anything do you want to share about the Life Plan?

62 responses

1. I don't know much about it.
2. Honestly there is no difference from our previous plan
3. My CCO knows less about the process than I do :(
4. We are waiting for the computer to do the I am assessment first
5. My MSC has continued as my Care Coordinator so the process has been sort of smooth for me.
6. I don't like the name at all. I mean can you plan out your whole life? Why should my son be required to do so? What if he changes his plans? The name suggests that because he has a disability that won't change, his life won't change, I find that kind of offensive.
7. Lacks person centeredness, providers not well informed of changes and the impact on their plans, meetings are way too long as provider work out fine details on merging life plans and staff action plans, providers have received limited guidance on staff action plans, technology is not working consistently- making long meetings longer, I Am assessment isn't picking up important details- which also leads to longer meetings.
8. I'm very hopeful as the information gathered from his I am will make life plan more relevant
9. Our Care Manager just copied and pasted from our ISP into the LP.
10. I don't think anyone knows how to complete one yet!
11. seems like it involves too much of my child's medical information and plans - things I do not need help with
12. Seem very much like the ISP with more health questions
13. It was comprehensive and addressed my child and her needs.
14. None
15. We will be completing it later this month
16. In Sept. we updated my ISP with the MSC--now that there are no MSCs or ISPs we were literally told yesterday we have to start from square one with a new Life Plan. That it will take up to two hours on the phone and more time in person. This seems like a terrible waste of time to start from scratch. Is there not one way for fields in the previous document (which exists in digital format) to transfer?
17. I'd like more information and an actual sit down discussion about the Life Plan and my daughter's services, and how it will change, if at all.
18. Our ISP was 04/18 and we have heard nothing official yet about the life plan
19. Confused about the whole change
20. We were told a life plan would be created but then the ISP remained in place and we worked on changes to the ISP.
21. Nothing
22. Because of my child's poorly understood disabilities, the life plan as the only instrument for which the comprehensive plan is managed has the potential for creating bias, misinformation and misinterpretation
23. I am concerned for my child's care when I'm no longer capable.

24. I can't say I have experience, but I can say that it sounds like bureaucracy and not person centered planning as per CMS regulations.
25. It seems to be progressing at a snail's pace. We are still waiting to hear about when the I Am will be completed. What we need more than anything is medical services coordination and I am still doing that long distance from my home in Maryland.
26. I do not know much about it yet
27. Don't know enough about it to ask how it will directly affect my young adult child
28. It's replacing the isp
29. I want to be prepared to fill it out. I went to the Manhattan DDRO meetings a few times last year to learn more about the entire process. That was how I learned about the process. I kept my MSC (who was new because the other one left apparently to do these new evaluations and personal circumstances as well.)
30. I completely disagree with the monthly required home visits. I do not have time for this and it is not necessary.
31. still learning
32. I don't know anything about it
33. All services my child receives, she received before the CCO. The Care Manager is uncommunicative and unhelpful. I will be asking for a change
34. Our MSC left her agency. That agency had a someone to cover until they "hired" someone new and that never happened and the coverage person left within a day due to pregnancy. Then, NO ONE RETURNED OUR PHONE CALLS. And to this day, no one has told us anything about managed care or life plans or anything. My son had to go to an RTF given his aggressive and challenging behaviors WHICH NO ONE HELPED US WITH. OPWDD and "emergency" means wait two weeks for anyone to call you back and then fill out this form.... really bad situation. They need to clean house and start over; put the money to the people, not to staffing more OPWDD employees who can tell you to fill out forms and do intakes. VERY BROKEN SYSTEM. I'm not for privatizing, but at this point, OPWDD is an agency that would make one wonder if it should be.
35. I haven't seen one yet
36. We are told it is replacing the ISP
37. There is a lot I do not know about it. Neither does my CCO
38. Have no info about a LIFE PLAN.
39. we are still in the process of it. I think it should be more focused on successful strategies in dealing with your loved one and should go more in depth about behavioral issues and long term goals.
40. Not all questions applicable about my child and had to leave a lot blank
41. I have objected to the CAS Assessment that was administered in Jan 2017 to my son and do not know where that documentation lies with the State.
42. The testing does not accurately depict his needs and I am worried it will have a bad impact on services to which he is entitled.

43. considering the invasive nature of the mandatory assessment, the 3 page form generated seems sparse and inadequate. it does not list true goals and very disappointing in general. in the process of revision
44. Not clear re this
45. I do not like all of the changes and how hard it has been for the care managers. Some are changing day to day and it is quite frustrating.
46. N/A
47. I'm deeply concerned that it is generated by what is input into the "I AM" assessment.
48. Wish I had a template or some idea of what the sections/format is
49. What is that? And how different from ISP plan. How the child's privacy is going to be protected
50. The delays getting a CCO and getting Self Direction approved are worse than ever for my family member as well as several of my own psychotherapy clients.
51. Not done yet
52. At present I am firing the CCO this better go smoothly as I am tired having no information & support has been so poor.
53. I nor my daughter's Broker can get a hold of the supervisor of this CCO. I am doing all the work to get services for my daughter. Very bad service.
54. I do not know if the life plan reflects what my son needs.
55. No set up for how to achieve goals. No accountability. No contact with sc.
56. It will be seated in a drawer
57. Our next group meeting will be a Life Plan
58. these plans are suppose to provide a customizable plan for the disable individual to live their best life rather than fitting a cookie cutter plan the insurance/CMS wants
59. Everything seems EXCEEDINGLY slow and no one really knows what's going on. Even the CCOs don't understand. And there seems to be a major backlog to even get a CCO.
60. It is not person-centered or individualized.
61. It needs to be more detailed and we need more services. Can't find respite workers there are not enough quality programs.
62. It's still a mystery.

What if anything do you want to share about the I Am Assessment ?

62 responses

1. What's the difference between the I AM and the CAS? Why do we need both?
2. I don't know anything about it.
3. We are waiting for the computer to do the I am assessment
4. It's ridiculously long and not necessarily appropriate for my child. For example, my child has autism and ADHD (and he's 11 years old) but he does not have mobility issues and his independence is already limited because he is a child. The I Am Assessment should not be one-size-fits-all, but perhaps it could be shorter if targeted to specific disabilities. If there are multiple disabilities, perhaps it is this one, but it could have been a lot shorter for my child.

5. started to try and fill this out but I don't know, don't remember and I'm not sure about a lot of things. I think I learned about the whole process first on the self-direction families list-serv and eventually my MSC/COO whatever told me about it but I really can't remember what, when and how. Also, I've had a lot of confusion. I thought we signed up for basic, the Care Manger says we signed up for comprehensive. But she says she's doing the I AM for us and only wants to ask us questions when she doesn't know - that doesn't sound right does it?
6. sounds way to complicated and poor use of resources with uncertain outcomes
7. Be prepared for a long meeting but it was a great time for really thinking about who my son is!
8. I have no idea what it is.
9. I don't know what this is
10. Way to long
11. My son lives in a group home. I am not 100% sure if he has or Has not done a I am assessment yet. I didn't think so.
12. It's essentially being done without me. Asked a couple of questions about my son's burial plans?
13. None
14. It was great and helped capture my son's preferences
15. I just learned about it yesterday from the new Care Manager but I don't know details. I'm definitely concerned about something she told me. She said that if your child has a developmental disability (mine does--autism) that the state now wants to newly delve into "mental illness" and test for that with a psychiatrist and track that. WHAT? And WHY would someone associate developmental disabilities with mental illness and WHY would the state want to track this and focus on this? Is not the chief goal of disability services to provide APPROPRIATE classes and services for families who (as families or as guardians) are responsible for determining what's needed with their own chosen team? Is the state to now align disabilities with mental illness? This is CRAZY! Many of us who have received Waiver Services for our kids for years (for us, almost a decade most of which has been with self direction) do NOT want the state to conduct it's own psychiatric assessments (to supercede what we have in place privately?), to draw false conclusions or make false assumptions about our kids or associate autism or other developmental challenges with mental illness. It's BAD ENOUGH the news does this. Every time someone does something horrible in the news they say "oh he was autistic" and people start falsely associating autism (specifically) with crime, with dangerous behavior and more. We have enough stereotypes to fight off. WHY is the state using this new I AM Assessment to pursue "mental illness" as if it's a global cover for all our kids? If someone wants to avail themselves of these addl. assessments or services fine, let that be a choice, but I'm very wary of this new "association" and profiling and also want to know who gets to see this--where the info goes (law enforcement? drug companies?). Autism is NOT mental illness but is mistaken for it way too often--let's not muddy the waters further. Ditto for other disabilities that mimic "mental" conditions. At very least families who have had appropriate and helpful Waiver services for years should be exempt from "new" mental illness investigations for their kids which might affect what they have or need--unless something is clearly warranted in the documentation--grandfathered, so to speak so you don't further "fix" what isn't broken (i.e what is working well).
16. We had the CAS Assessment, is that the same thing? I wasn't pleased with the CAS Assessment
17. I have no information. Therefore, I can't share anything about the I Am Assessment.
18. We do not know anything about it aside from the fact it is very lengthy. We are looking for a new CM our present CM knows nothing about SD and asked inappropriate questions about SD at our launch further indicating they know nothing about SD.
19. Again co fused about that also
20. I have never heard of the "I Am Assessment."

21. Nothing
22. OPWDD needs to communicate definitively that the I AM is not required for people in Basic.
23. It is the antithesis of person centered planning for people with I/DD as it doesn't address the long term community supports and the obstacles to getting them.
24. I don't understand it. We had someone come for 3 hours to do a CAS assessment. We had SSI intake, Social Security, OPWDD initial intake and more.... how many more do we need? This is on top of all our daughter's extensive medical assessments and reports that have been shared. This is becoming wasteful, time-consuming and emotionally draining.
25. Some of the questions were stupid and unnecessary
26. haven't taken it
27. I want to know specifics about how this document will be used to determine any services for my son
28. I have sat with families- while doing the I am assesment- most care managers do not know how to use the system- you can not pick more that two valued outcomes under my happiness -
29. What is it? How do I learn about it?
30. Some of the questions for my son were inappropriate and completely irrelevant for someone his age. A complete waste of my time.
31. No
32. ?
33. When the hell will my child get this
34. I don't even know what it is.
35. It should be a program a parent can fill out at their leisure and ask for assistance if they require it. It is not user friendly for the participant.
36. Have only seen it in a professional Broker capacity. Many of the questions are ridiculous
37. I hope that NYS will stop trying to fix things that are not broken. I AM is a bunch of malarky and unclear in its questioning. It is also very invasive. I do not understand how the information will be confidential. Where does it go? Who or what entity is in charge of protecting privacy?
38. Have not done it
39. It should have more focus on realistic future goals and current issues that are not being addressed.
40. Not sure if it will be beneficial for my daughter's needs. Will know in the future.
41. I don't know anything about it other than references to it from general public meeting about the CCO roll out. BTW I was JUST contacted by my Case Manager a week ago after I initiated contact with the CCO's ED (!) over a month ago because a phone message was left at my home with no reachable number.
42. In response to earlier question- Have you ever been told ANYTHING about the "I Am assessment" from OPWDD or your CCO/HH?" the answer is yes. Have we been told much-NO!
We have not yet participated, but were just informed today that OPWDD has mandated that it MUST be completed by Dec 31--. We are mostly concerned about the lack of communication about how this information might be USED to determine level of support needs...or types of supports or recommendations from a future, yet undisclosed managed care team with a yet undisclosed set of procedures. While it might be better than the planning tools previously used by traditional services, no one should fool themselves to think that this interview can possibly substitute for a well developed person-centered planning process!! have no idea what is going on.
43. I don't even know what half of these terms are.

44. took over 2 hours and demanded a lot of irrelevant or invasive information. the computer program was troublesome and it is unclear why i needed to disclose the type of burial my son would require.
45. Not enough info
46. Too much ridiculous information asked...why do they need to know my 13 yr olds funeral plans or what scent candle she likes?
47. N/A
48. I am very diligent about keeping informed and was lucky enough to get a peek at a pretty comprehensive list of questions on the I AM assessment through a local advocacy group. Because I knew ahead of time what the different sections of the assessment were, I was able to question my Care manager as to why certain questions had not been asked that were highly relevant to my son's case. She went back and ticked a box that had been left unticked and the entire section I had been referring to appeared on the screen.
49. There were also a couple of occasions where we were forced to choose a single option when 2 or more would have been appropriate. I was later told that this was a glitch and that the MSC/Care manager would have had to scroll to another section of the page to be able to check multiple options. I haven't been able to ask for this change to be made to my son's assessment.
50. Long and not sure what the impact is on child's current services.
51. What is an I AM assessment? Do not assume that everyone understands the abbreviations.
52. Not yet done
53. I never got any information
54. It was haphazard because the technology was not working properly.
55. Not beneficial. Goals are to remain safe and have family member present.
56. Nothing with mention of obtaining equipment or necessary resources.
57. Too long, too useless, better to play guess
58. .?
59. seems to want the individual to conform to whatever ideology CMS is wanting rather than accepting and supporting the real individual as their self
60. It seems to have an institutional bias. What I paid caregiver would need to know vs. information that would generate a truly individualized Life Plan. Even in that regard, it is lacked. E.g. asks about dental hygiene but omitted an inquiry pertinent to my son.
61. A lot of it did not apply to my daughter. It appears to be created towards folks that have a higher skill level.
62. The I Am form is 62 pages of questions that seem to have been prepared by someone who never met a person with a developmental disability. The form poses broad questions but offers limited choices for answers which do not allow for an accurate description of the individual. Since this information will subsequently be used to determine what services an individual will receive, the limited choice of answers will surely result in service cutbacks.

Please Provide Your Feedback about the Transition from MSC to Care Manager ?

100 Responses

1. is whole thing is an unnecessary process, needless complicating the lives of disabled people with an additional layer of essentially-meaningless bureaucracy.
2. care manager less available
3. Too rushed, technology wasn't ready, not enough training available on what really matters, not enough education for providers (hab providers)
4. We had no issues transferring
5. Confusing
6. Care Management was designed to manage medical and mental health care when others were misusing services/having too many ER visits. I dislike that model is now carrying over to the OPWDD world. A default consent form for the Care Management has a sneaky line that basically says "All doctors or PCP" before we lost our current doctors. I crossed out that line as I don't need our Care Manager harrass our PCP when I am perfectly competent to manage my son's medical care. I prefer to scheduling doctor's appointments for when I am available and not if or when our CM wants us to.
7. It hasn't been rolled out smoothly, but OPWDD was given an unrealistic time frame to complete the transaction.
8. It's been very poorly managed. I had more info than my MSC/care manager did.
9. the only reason I know my Care Manager was that I reached out to my MSC on her last day, and she forwarded my info to her and cc'ed me on it! But there's been no outreach from the Care Manager since the transition.
10. A shameful disaster.
11. Nothing to report - took two months to get a care manager and have had one meeting after screaming and shouting with excessive emails all over and to everyone concerned at the agency that dumped us.
12. Very easy
13. Sloppy and poorly managed. Feel lucky that my MSC is also our CCO! Many people got lost in the transition and still do not have a CCO.
14. My MSC became a supervisor and I was given a new Care Manager, I have worked with her in the past as a temporary MSC . So we are able to work together to get any paperwork done. I am sure we will do the I am when they are given the computer they need to do this.
15. I believe thty sure OPWDD already knows about all of the problems you're "identifying" with this survey. Advocacy groups should be focusing their efforts on helping to get things on track rather than complaining about things via a survey.
16. terrible - for a while i didn't have her proper phone number or email - even though she had been my MSC. She had me sign a paper for the higher level of coordination without presenting me with

the Basic option. I requested to be on the Basic plan because I don't need constant coordination nor help with medical issues

17. Too little or non information have been given to me about it
18. It wasn't any big deal for me because Linda Schellenberg found me a new MSC since my MSC left right when the plan was changed and I really depended on Linda and my new MSC to take care of everything and I trusted them and I still trust them but I'm lucky.
19. It has not been smooth. I had to reach out for the name of my care manager. Did not have one until almost Sept. There is confusion about my son having basic - that he should have comprehensive but could not get an answer as to why. With SD not sure I how much help I will need to help us - only need help at this point if FI says need the care manager involved.
20. Both the MSCs and consumers are not given enough information
21. Families need to be more informed about the Life plan, I Am assessment and privacy rights
22. So far there have been no issues.
23. In my case it is the same person.
24. I have a great MSC and she has answered every question I have had and provided guidance.
25. None
26. Our care coordinator has been great; we've had a seamless transition process
27. A bungled mess. Nobody at SKIP knew WHO would be helping us. There was initially a hope that supervisors at least might be watching our kids' "cases" but then we learned last minute that would not happen because there were different levels of care and no supervisor could take on a caseload that would "conflict" with that (which makes no sense) and that supervisors in Manhattan (SKIP was in Manhattan) could not help Brooklyn families (SKIP served all boroughs). The letter I got had no emails for the Care Managers. I figured it out (from the email for the higher ups) but this is the 21st century and having an email contact is important. Also, nothing in the letter said anything about what would happen, how services would continue. Our new care manager was very nice but had no idea about my daughter (at SKIP new MSCs were supposed to read the case info to become familiar with those to whom they were newly assigned) OR about what records were or were not transferred from SKIP. She later (on the call) was able to look up to see that her records were "up to date." It seems that we parents are in for a LOT of work ahead to accommodate what seems to be a clunky, invasive, and possibly far less personalized system
28. I think there may have been conference calls about the transition which I was unable to attend and now I feel completely lost
29. No one has actually explained anything. That's why I am possibly interested in a new MSC.
30. These ridiculous acronyms are nothing but medicaid speak and is shameful evidence of why you-OPWDD bureaucrats should get off the states' payroll and stop making my ability to take care of my daughter more and more difficult and complicated. This is nothing but BS . Nobody on this planet has ever heard of life plans, DDP2s , CCOs. - under the guise of some medicaid program ? Shame on you. I pray for day soon that this entire process becomes subject to the federal courts so that this BS will stop .
31. CCO yes care manager no. We want to move on and would prefer no setbacks for being honest.
32. It seemed as if the MSC did not have all the information in order to provide it to me.

33. For our family it was smooth. The agency providing MSC services contracted with the CCO for one year so that all our services and contacts would remain the same for one year.
34. We have had three Care Managers since August. So far none of them have been able to explain the program. The second one knew absolutely nothing and couldn't answer any of my questions
35. I had to email to find out who my care manager was..no one told me anything
36. impersonal with many delays in getting important services
37. I haven't been able to get any of the approved services and the coordinator rarely returns my calls/emails.
38. I feel that we have been somewhat protected during this transition because our former MSC agency (Job Path) took advantage of the 1-year transition period. Our current Care Manager is, fortunately, the same person as our former MSC -- and is still "housed" at Job Path. This has at least provided us with some consistency during the transition period. Once we lose the connection with Job Path, I have no idea what will happen. Probably nothing good. Advance Care Alliance has been inaccessible by either phone or email.
39. My son's MSC is still is care manager. And that is a good thing. Paperwork is still trickling in. No new service or support is provided in this CCO structure that would provide my son with additional supports or services. Nor does this process speak towards the sustainability of Self-Direction, as it was billed by OPWDD
40. Parents need a newsletter monthly from the CCO telling us what the progress has been. I cannot see how Life Plans will be completed by July at this rate, nor when I will have someone in New York overseeing medical care.
41. This transition has been onerous and far less than satisfactory. The new "people" we have met to represent CCO have not been prepared and instead of helping us have made the situation more difficult. In fact, some of her questions have been insulting and made it clear that she had not read the extensive paperwork on our daughter's situation.
42. Had a Msc for my younger son with head injury assn for nine months that I was happy with and wanted to transfer my older son who was with citizens and was dissatisfied with to head injury provided I would have the same care coordinator for both boys. Head injury was made aware of this a few months ago and told me they would give both boys the same care coordinator My older son was going to be transferred to head injury on Sept 1 which eventually turned into October. 1. On October 9 head injury tells me that my care coordinator was promoted to another position and will no longer be serving my two sons. I was given a new Care coordinator for both my boys who does not have much experience and Is not too knowledgeable about things. I also had an annual isp meeting for Both boys in October. NOW after doing the I am assessments I am told that I Did not have to have isp meetings but still have to have family care meetings for Both boys by the end of December which are currently scheduled
43. Our transition was fairly smooth - we knew what to expect We did have a change I care manager(our care manager , formerly MSC was promoted to supervisor) but that went smoothly as well We did not attempt to get any additional services (don't need any at this time) so can't

answer the question about service acquisition. Still have all the same services as before - no loss/ no gain. We experienced little change with the conversion to CCO

44. it is BS
45. Awful... received one phone call where was notified my MSC of 3.5 years was no longer going to be working with us because she was assigned to only Tier 4 people. There was no transition time whatsoever ... and i now understand the Tiers were not even properly determined as there are level 4 individuals that are inaccurately placed based on how questions were asked in the Tier process. We have invested time into our team and into the relationship our child has with his MSC and are very sad about the change that we had NO say in.
46. Disaster. Total confusion, no one knows much about anything.
47. I learned about the life plan and I am assessment from Non OPWDD parent groups. Not from my MSC. You left out the evil CAS. (Consolidated Assessment System) we did a CAS for my daughter when I read the assessment Most of the info collected by OPWDD's professional was wrong. It made my child much higher functioning than she is
48. Could have been handled better.
49. I have little information. My son's previous agency stopped provided care manager with no notice to us. Received a call from someone saying they were from his CCO- nothing in writing and we are still waiting. Very worrisome!
50. Personally I read all information from opwdd that is now I am informed
51. It has been extremely difficult to contact the MSC to find out anything.
52. My child turned 21 in July so we had already set up the dayhab etc but it's almost like we had to reapply. There was no set system for the transition. When we needed paperwork that I didnt even know we needed, there was no way to get it from the CC Agency- Tri[something]. It was through my persistence that the Dayhab intake person helped us coordinate getting some form uploaded to the platform that the CC orgs were using. TriCounty was not up to speed where as the CCorg (I think ADAPT was and through this connection we were able to get my kid into the system. The CCCs were very frustrated as well. Infact they still use the old agency email because they do not yet have one for TriCounty. Also I am signed up for comprehensive level rather than basic and am not sure what to do in this regard . Also almost approved for SDirection .
53. I still don't fully understand
54. It had been terrible being that my care manager has been changing on an almost months basis. I can better answer this question after I get to know my new CCO.
55. It seems shaky at best
56. My transition was smooth. Because I work in the field and understand the system I have not had any surprises yet. I am sure they are coming. In terms of communication and roll out and how the transition occurred without full comprehension of stakeholders, that is not only a wider problem for the system but also the indifference of families'.
57. I dont understand what is the difference ,its seems to be just a name change
58. Very frustrating I'm still with out services
59. Effectiveness boils to the person, not the position title. We had a great MSC, and several lousy ones. This Care Manager is lousy, but I think it's because she's overwhelmed with cases.

She even gave me the wrong email and didn't correct this until our broker contacted her supervisor. This took over a month This transition hasn't improved care. It won't until there is adequate staffing. And better hires

60. I am disappointed that my Care Coordinator, who was also my MSC, is not helping with medical/health care of my child. I still have to do everything myself. I don't see any improvement yet with the new system, which was supposed to go into effect back in July
61. Transition is always very confusing
62. It has been terrible. The agencies were not prepared and I am sure OPWDD was hoping for some kind of attrition which is terrible and causes problems for the people who need us most. My son has been suffering terribly in the past 2 years and OPWDD has been absolutely useless (as the state and all supports BTW). If you want to talk, you have my email. I just need to support my son's crisis now and try to get to the next phase which is moving him to housing. and no agency will want him because he can be aggressive and is considered a "high needs" case. Sorry, I could go on....thanks for doing this and I hope it gets somewhere. Note that I do believe there are really good people at OPWDD- it is just mismanaged and NOT transparent.
63. When transitioning from old to new, my receipts for family reimbursements were deemed ineligible because of the timing of the receipts. My MSC was supposed to be my care manager but he was promoted. The new person is okay.
64. We are fortunate our care manager is experienced and knowledgeable. Unfortunately, that is not the case for many. The new care managers are very confused and so are parents. There is no up to date information for the brokers who will be completing the action plan.
65. I feel it should have been rolled out and explained in a much more detailed format than what was provided to families, Care Managers, Individuals and their families. In my professional role, most MSC's were still quite confused themselves and were unable to present a detailed explanation of the switch to CCO, leaving most of the families I deal with very confused and not understanding the changes being implemented.
66. Very Rocky. Had 3 interim people so far since change from MSC. Meeting NEW Care Coordinator after Thanksgiving. Scheduled to do I Am interview.
67. My son is a tier 4 so we have started this with our msc. I have heard many labeled with tier 4 have lost their msc. So far we have not. We are still in need of hands on services for crisis behavior and have staffing issues- same as before.
68. Seems too difficult to manage the IAM APP and now am having a longer wait time to reach my Care Manager
69. I am greatly concerned about protecting my son's personal and confidential information from those who seek to profit from the CCO/ managed care "roll out."... Last May we were informed by letter from our former CMS agency about the CCO transition but our MSC did not know a lot (did anyone?!) In June during our meeting with the CMS I/my son refused to sign a HIPPA release to have his privacy data shared with anyone other than the previous MSC's agency. In late August or September we were informed of the identify of the new Case Manager by the soon to be former CMS agency and assured that the person who would be leaving to work for the designated CCO was briefed on our privacy concerns. In late September two messages were left on our home

telephone machine but the number that was left did not have any identifying information and I could not reach anyone on the number. I eventually emailed the CCO's ED and was contacted a week and a half ago by a supervisor for our son's new Case Manager. During a scheduled call last Monday, the supervisor informed me that the Case Manager had been changed and that she could not speak with me about my concerns until I produced a copy of my P of A (which should be in any file maintained by providers...). I suggested that they get their HIPPA release to me and my 26 year old son before we talked to them. (I also expressed concern about their having changed the Case Manager over the weekend after confirming the identify of the person who had been provided to us in August.) We have received NO WRITTEN INFORMATION from the new CCO except the email from the Case Manager introducing herself a week ago. We know nothing about what is supposed to be happening now.

70. Horrible. The agency told us we could not have the basic plan. We were dumped by the agency without warning two days after they demanded a meeting to update the ISP. Now I need changes to the ISP and the agency didn't handle it. New CCO knows nothing about us or our history. No ISP and it is now out of date. So, do we lose services because we are out of compliance??
71. for us it has been relatively smooth, since we maintained the same who has worked with our son for many years (from a quality organization). So far, care Design has seemed to be relatively responsive -- Less than one week into the transition, they announced that "supervisors" would not be permitted to have a case load of their own...which would have meant a change in CM for my son-- absolute contradiction the the promises made about "transition with your MSC!". After pushback from CM and from families, Care Design reconsidered and permitted supervising CMs to keep some participants on their case load. However, It has been disturbing that OPWDD seems to send out new regulations to the CCOs and the CM at the last minute, with new rules, procedures or expectations.. with little lead time and sometimes with little rational. MANDATEs regarding frequency of visits (monthly) for tier 4 participants, and mandate of Dec 31 IAM and Lifepans ordered by OPWDD, with little room for negotiation... putting extraordinary pressure on CMs and mandates on participants before many of the kinks have been ironed out, or the procedural questions and challenges have been answered.
72. My previous MSC is my current Care Manager
73. it is unclear what has changed or what services, if any, are now included or removed. i am not even sure to what extent the manager is supposed to managing. I am greatly concerned that the manager will not be independent assessors of my son's needs and will be pressured to cut or disallow vital services in order to lower their budget to my son's detriment. The "transition" has not been clear to any one i have discussed this matter with, in any capacity. i still do not know the extent of the "management" that is to be provided. the primary obstacle of not having appropriate and adequate staffing remains constant. I am just glad that the much needed services that i have been able to put into place have not been disrupted and the case manager is bright and truly trying to help.
74. Confused!?

75. My MSC was promoted shortly after she switched to being my care manager. I have yet to meet my new care manager.
76. Confused everyone is confused
77. Went to a number of meeting on the transition to CCO and Care Manager
78. I have not spoken to the Care Manager since the transition took place. I was successful in changing my son's day hab program in late August, because I submitted most of the required documentation myself. I emailed the MSC/Care Coordinator to request that she forward the one or two items I did not have access to. As far as I know, she did that because the new program has not indicated otherwise.
79. The only contact I had with her leading up to 7/1/18 was when she needed me to sign the enrollment paperwork. I have not spoken to her since.
80. As the change was happening in July of 2018, my MSC quit the agency we were using, giving very little notice and we were left without an MSC or a Care Manager. I had to raise holy hell with supervisors at the agency to get assigned a new Care Manager. It was terribly stressful.
81. My daughter has been designated Tier 4 - highest need - yet the care manager assigned by ACA has no experience with Medicaid and has not been trained. If we lose Medicaid benefits owing to this it is just a lawsuit waiting to happen
82. Was just told what their recommendations were, cookie cutter approach, not based on specifics of child or type of family/ need/ interest
83. My child's medicaid was terminated by the error of HRA in September, when I called MSC/Care Manager, I was told because I signed up for the basic plan, they do not need to do anything. I heard from other parent that if I do not sign up for the comprehensive plan, the care manager would not help in keeping the straight medicaid. I was told the parent needs to be on the top of everything, if I have a basic plan. I would like to know why MCS/Care Manager so badly wanted me to sign up for the comprehensive plan, what is the difference between comprehensive and basic plans, and what is the advantage for signing up for the comprehensive plan if I want to pursue the self-direction. I also would like to know what is the future of the self-direction would be.
84. If it were not for my broker who is an independent, I would not be aware of any of the things mentioned in this survey. I learned about the I AM Assessment from my broker and another special ed parent. I have had 3 different care managers since 7/1/2018. One of them set up an ISP meeting and quit and (Head Injury) never told us. I had a room full of people and no care manager.
85. Terrible for the many families and consumers who I know. The new system was reinventing a wheel that just needed to be oiled, not replaced. Too many lives are affected and the people staffing coordinated care and services have been turned upside-down.
86. I AM ABSOLUTELY ADAMANT ABOUT ENSURING MY PRIVACY AND THAT MY EMAIL IS NOT ASSOCIATED WITH THIS SURVEY SO PLEASE TAKE THE REQUIRED PRECAUTIONS. The transition has been disturbing on several accounts. Our new care manager informed me he can not find certain required paperwork for my child. They came over for a meeting and I asked them if it was a circle of support meeting or a semi ISP and they didn't know. They didn't know why they

were there. It was their job to know that. My care manager has told me he is available for any help needed. However when I have asked for help there is no response. He is brand new and so is his supervisor. I miss our old organization which seemed to understand what the requirements are not to mention getting help. I do NOT want to have people coordinate my child's health needs. I do NOT want monthly meetings and that's what I would have gotten if we chose comprehensive due to the nature of the disabilities. So now I have NO help with coordinating / getting needed OPW services. The transition came with an ultimatum that I would have to also have my child's health care needs coordinated. The time issues for this are ridiculous. I do NOT want or need monthly in person meetings. I can not lose the time from work for that! I do NOT want a four hour IAM assessment. It is an invasion of privacy. I have yet to see how any changes that are instituted will help my child.

87. All the information I got was when we were doing each step. I'm sure there is information I haven't been given yet.
88. Didn't expect anything to change for the better as the MSC was never around or helpful. No surprise, she is the same. Months on end we don't hear from her & if I call her goes to voice mail & maybe she will call back. She is not informed herself yet prides herself working 17yrs. as a MSC. We moved & she didn't want to change address do to all the paperwork. I could go on & on. There is much more that I think is more serious but I don't have all the time since I am doing all.
89. My son has had so many MSCs who really do not get to know him. The Care Manager did the assessment on the first day she met my son.
90. I don't understand why this is necessary
91. Had no sc for several months. Told to contact supervisor with no response until the third message. Not happy with the program at all. Over three months without contact from sc then told our stuff put on hold for more needy participants
92. Waste of money. Needed "I don't know" or "not sure" to answer most of your questions in this survey. They won't listen to this survey anyway. Life Plan for me is due by Dec 2018, more ridiculous.
93. I was never notified that I had been assigned a care coordinator (We went from SKIP of NY to ACA). Meanwhile, our LOC was about to be overdue. I had to call/email Ellen Bleckman at OPWDD for help. Her office provided me with contact numbers. Nigel Nero at ACA got the ball rolling. I met with Tanya Brown, the care coordinator's supervisor, and the care coordinator (who did not say one word the entire time). The LOC was completed. The first care coordinator then was moved off my case and I was assigned a second care coordinator. She is incompetent (I asked for an ISP amendment and sent her a draft. She said she completed it and sent it to my FI and Broker but they never received it. She didn't know it had to go to me as well. She couldn't operate her own computer to complete the IAM assessment and she is unresponsive to email). I asked Nigel Nero to assign me another care coordinator. He has reached out to Gabriella Medina, who is the supervisor for my area (Brooklyn) and I am supposed to hear from her asap. If I don't hear from her in a timely manner or if the new CC is incompetent, I will lodge a complaint and switch agencies.
94. Went fairly smoothly for my two.

95. No choice, just moved past it
96. No one knows what's going on.
97. I changed CM on 6/30 because then MSC wouldn't confirm that she was continuing with CCO.
Then abruptly lost the new CM and notified of that in early November. Because my son is Tier 4, Life Plan has to be completed by `12/31.
Not likely to yield an accurate or helpful document.
98. Not enough information was given and I still don't see the benefit of this transition. I know the federal government made New York do it but I don't see any new Programs or services being offered.
99. It seems we are adding layer upon layer of bureaucracy, the cost of which will reduce funds available for actual care.
100. Seems like there is more to it than I am aware of. I will discuss these with my care coordinator.