



April 26, 2019

To: Department of Health
DDSD
Lisa Storti, Office of Constituent Support
Christina Hill, Community Programs Bureau

Re: Public Input Supports Waiver/ Other Waiver Considerations /Definition Feedback

Thank you for your request to provide input on the new proposed Supports Waiver.

The Arc NM appreciates the efforts on behalf of the Department of The Health to provide services to individuals who have waited for services too long. We understand the costs of the two existing waivers in a state as poor as New Mexico has contributed to a long wait list and that this supports waiver provides the potential to improve the lives of individuals with developmental and intellectual disabilities. While we are providing some considerations in developing the supports waiver, nothing that we are providing should be interpreted as less than full endorsement of a supports waiver to be implemented in January 2020.

Attached is a position paper with 8 sections:

- Introduction
- Paradigm shift
- Definition of Development Disabilities
- Assessments
- Strengthening Workforce
- Supports Waiver
- Self-Directed Waiver
- Summary

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Position Paper

Improving Services to Individuals with IDD

In the State of New Mexico

Section 1. Introduction

The Arc New Mexico advocates for individuals with IDD to live in their communities with supports specific to their needs. Waiver supports should provide for maximum health, safety, independence and full community participation and inclusion. Towards that end The Arc New Mexico supports community based waiver system(s) to assure that individual needs across a lifetime are met in a cost-efficient manner. Without a cost-efficient approach to services, many New Mexicans have been forced to wait for services. The Arc NM appreciates the development of a supports waiver. We believe this should be developed along-side reforms and changes to the other waiver systems and with a long term approach of having one waiver system flexible enough to suit the needs of all individuals and with zero individuals waiting for services longer than 90 days.

Section 2. The Need for a Paradigm Shift

The Arc NM believes that most individuals with disabilities want to live integrated full lives with only the services they absolutely need to be healthy, safe and productive. We, also, believe that currently many individuals on the traditional waiver are receiving services that are more than they need at the current moment to achieve that end. The Department of Health have attempted several different cost containment measures over the last decade which have failed to contain the cost. In fact, it is the position of The Arc NM that those cost containment measures have only increased the cost of services. Individuals and their family members on the current traditional waiver live in fear of services they are receiving being taken away or not being able to access services should they need them in the future. The attempts at cost containment did not work specifically because they have inspired fear which caused individuals and their support systems to maximize budgets, justify services in a deficit based manner and discouraged services such as employment or independent living which might be seen to indicate a person would no longer need as comprehensive supports. Individuals and support systems were sometimes forced to ask if they would be able to justify a return to supported living if independent living skills fail or if they would be able to regain the full amount of behavior therapy should they reduce the service for a year or two. In an era of fear, it might be seen as better to stay in a higher cost category than risk losing them and not having them when needed.

The reality of the human condition is that support and medical needs change for everyone over time. The same is true of individuals with IDD.

The Arc New Mexico takes the view that cost containment should be seen as an outcome of a person centered approach which encourages independent skills building and community participation as oppose to cost containment being seen as limiting the services available. Flexibility to change budgets or service systems as needs change would allow individuals the security of knowing their needs will be met without attempting to maximize budgets now to be sure they can have access to services should they ever need them. We understand this seems

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counterintuitive. If the Department of Health believes that individuals and families want as much as they can get out of the system without regards to the actual needs of the person, then a cost containment and limitation approach makes sense. However, if the Department of Health could embrace the concept that individuals with disabilities want to live integrated full lives with only the services they absolutely need to be healthy, safe and productive, then cost containment could be seen as an outcome of a person centered approach which encourages independent skills building and community participation.

If New Mexicans with IDD and their families were secure in the knowledge that individuals could reduce or increase services dependent on their changing conditions then individuals and their families would have less of a desire to maximize budget costs. The systems would obtain cost reduction by encouraging persons to work, live independently and reduce services during periods of their life when their health and skills achievements allowed them to reduce cost. It would allow individuals and support systems to increase services when health conditions warranted or when increased services could be used to build skills for the next level of independence.

This is a paradigm shift which we do not expect can occur by 2020, but which we would encourage the Department of Health to consider how to transition to over time. We believe the Supports Waiver implementation by 2020 could be one step towards achieving that paradigm transition.

Section 3: Definition of Developmental Disabilities

The Arc NM supports the decision by the Department of Health to go to a more functional assessment of developmental disabilities in keeping with the best practices across the country. However, it is important that anyone who has been deemed qualified under the current definitions should not be adversely impacted by a Definitional change.

Section 4: Assessments

The Arc NM believes that comprehensive assessments to determine current needs are needed for both individuals who currently receive waiver services and those on the wait list. The Arc NM would support an assessment and assessment process which incorporates the following:

- Individualized to reflect complexity of strengths and challenges and personalized goals
- Individual participation as the focus of the assessment with family and others who know the person best providing input
- Completed with full transparency as to the process and purpose of the assessment including consideration for individual /family/ others ability to comprehend the process and purpose (i.e., language, literacy)
- Recognition that needs change over time; sometimes abruptly, and that any assessment can only reflect the current status
- Opportunity for full due process to challenge the outcome of any assessment

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Section 5: Strengthening Workforce

The Arc NM encourages the Department of Health to consider the crisis in direct support care professional workforce and work to develop strategies to overcome this within the two current waivers as well as the one proposed. As these positions have become minimum wage positions within the delivery systems, the administrative costs for incident management and regulatory systems have risen. The Department of Health should consider whether the impact of raising the salary levels and professional standard of Direct Support Staff could decrease the administrative costs of some of these other systems. This would have the benefit of putting the dollars towards service and the provision of quality care instead of continuing to increase the costs of investigating after services have failed.

A strong workforce could also be successful in delivering the intent of the service delivery in terms of employment and independent living. If more individuals capable of working and living independently were achieving those outcomes, then cost containment would be achieved

Again, we recognize that increasing the costs of wages seems counter-intuitive for cost containment. However, resource management does mean prioritizing where to expend the resources to be most effective. The Arc NM recommends direct care staff as being a priority area to expend resources.

Section 6: Supports Waiver

The Arc NM appreciates the commitment of the current administration to reduce the wait list by having a supports waiver. We, also, appreciate the work and research that has already been completed.

We would like to point out that the eight states in which New Mexico is looking for models that might be replicated are all states which continue to have institutionalized settings. We have reached out to The Arcs in these states to inform our feedback. In at least one of the states, Ohio, advocates are seeking to combine waivers because having more than one waiver is confusing to families and their supports. In another state, Louisiana, which has implemented a supports waiver in the last year, there is concern about rising costs of all waivers in the last year and a fear among some advocates that families might see institutionalization as the better option than community supports with limitations.

We are not suggesting that these facts discount the results that the states have had or that they should not be followed. We are only reminding the Department of Health that the fact that New Mexico is only one of 14 states to eliminate institutions should be celebrated, but should, also be considered as to how it changes the reality of service provision. Additionally, we believe that there needs to be careful planning to mitigate the confusion that having multiple waivers might cause. People are already confused with two waivers, centennial community based options and wait list services (SGF services).

The last point is especially important in terms of individuals retaining their place in line for the traditional waiver while accessing the support waiver. Safeguards should be put in place to

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assure that individuals and their families are not encouraged to give up their places or are confused about still needing to reply to requests from Department of Health regarding the traditional waiver. The systems differentiation and remaining on the wait list for the traditional waiver must be clear. A menu of options for individuals and families might be a longer term approach to eventually having one waiver system.

The Arc NM appreciates the ideas for New Mexico includes employment, Self-Advocacy Training and Community Coordination. We note that the Maryland model includes employment discovery and customization. With the statement outcome to focus on transition from school to employment, we encourage the Department of Health to consider short term funding beyond the budget to allow for one time discovery and customization of jobs. With the current concerns related to DVR vacancies rates and order of selection, this is a service that is needed. Attention to assuring a focus on employment might reduce the long term cost both for this waiver, and once the individual is on a more typical waiver system. We are, also, happy to see budget and money management included on the ideas list. We would, also, recommend including the friends and relationship class and other community classes that would increase social inclusion skills and academic learning onto the list.

Finally we would like to address that the supports waiver ideas does not include case management, but might include some self-direction supports. We recommend incorporating some of the developing practices around supported decision making into this waiver to encourage individuals the option to select family members or other community supports or friends to aid and teach decision making skills.

Section 7: Self-Directed Waiver – lessons for the support waiver

As New Mexico is developing the supports waiver and looking at having a self-directed component, it would be foolish not to look at the problems with the Self- Directed (Mi Via) Waiver. The Arc NM has been and continues to be a strong proponent of the Self-Directed option, but we have increasing concerns about the way this waiver is being managed and the increasing costs. Since the implementation of the Self- Directed waiver in New Mexico, labor laws have changed on a Federal level when it comes to the definition of employer and shared responsibilities. There is currently vast confusion about the unpaid employer of record role in this waiver in addition to the concern of the hands off approach by DOH. There should be a comprehension examination of this for the current self-directed waiver. At the very least, those issues should not be duplicated in the supports waiver. How does the Department of Health propose that individual direct support be hired in the supports waiver?

We encourage the Department of Health to develop some type of directory where staff looking for work and individuals looking for staff can register to counteract some of the issues with finding staff when family members are not going to serve that functions in both the support waiver and self-directed waiver.

The crisis in finding staff have led many families and individuals to select agency providers. This has not only increased the cost of this service, but has the potential to hurt the self-directed

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nature. We want families and individuals to have the option to select agencies, but believe that the Department of Health could do more to provide support to families who are searching for direct support staff instead of resorting to agency provision of services. Finally we encourage the Department of Health to consider what type of oversight might be allowable under this waiver without adversely impacting the self-directed nature. The lack of oversight have meant, in some cases, abuse of large salaries to family members while individuals remain isolated and vulnerable.

We bring these issues up in this document because we do not want to see a continuation of these problems in any new waiver and would like to see efforts to correct these problems in any existing waivers.

8. Summary

This is an exciting time for New Mexico with the development of this waiver and with the opportunities afforded by the possibilities of disengaging fully from the Jackson lawsuit.

While we applaud the decision to have a supports waiver in New Mexico beginning in 2020, we continue to believe that the best approach would be to have one comprehensive waiver with a menu of options reflecting specific needs. With a paradigm shift that eliminates fear and encourages employment and independent living, there should be no need for individuals who don't need to maximize budgets to do so in the traditional waiver which would end the need to have a separate waiver. Additionally the fact of a self-directed waiver implies that the traditional waiver is not self-directed. However, every individual, regardless of the waiver supports they receive, should have the flexibility to select and define services for themselves. This is a long term strategy which will take time to implement.

Position paper developed April 2019

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