

Alberta Association for Community Living (AACL)

Response to

PDD Community Conversations:

Supports Intensity Scale (SIS)

June 2014

The Alberta Association for Community Living (AACL) welcomes the Persons with Developmental Disabilities, Alberta Human Services inquiry into the experiences of individuals, families, guardians, funds administrators and service providers with Alberta's use of the Supports Intensity Scale (SIS). While AACL believes there should have been far more consultation and critical appraisal of Alberta's utilization of SIS, as noted in government commissioned reports as far back as 2007, we welcome this opportunity to contribute. AACL's critique of SIS should not be construed as a critique of PDD or government's direction, which we support, but of the instrument itself and the beginning unintended consequences that have already risen in regards to its use.

AACL has two overriding objections to SIS, one of which is unalterable as it rests on ethical and moral principles

1) Categorization and dehumanization: Currently PDD implies that SIS will be used to determine funding (<http://humanservices.alberta.ca/disability-services/pdd-sis.html>). The implication lies in two statements on this webpage. One states an individual's funding will remain the same until the SIS is completed and another that prior to SIS, PDD did not have a consistent means of determining funding. At this time it is not clear what PDD's intentions are with respect to any future relationship between funding and SIS. Currently, AACL has direct knowledge from the experiences of families from 3 of the 6 PDD regions that SIS is being used to not only determine funding, but what types of service to be provided, whether an individual will receive the supports they request according to their goals and aspirations and/or an individual's priority placement in receiving needed or requested services. These regional actions are occurring although PDD itself has not publicly declared how or if SIS is to be used for determining funding or any related factors. This would be an opportune time for PDD, given its stated commitment to transparency and responsiveness, to declare its intentions with respect to SIS and the allocation of resources (i.e., funding).

Hosting a conversation about one's experience with SIS is fine but if the totality of the experience has not yet been forthcoming, such as SIS's role in determining funding, than the conversation is rather limited given the life-defining power of funding. In fact, the primary concerns expressed by

most of those who are subjected to SIS is with respect to its relationship to funding and not to the SIS supports profile which is independent of any funding formula. In one of the government's own commissioned reports there is repeated reference as to how to protect the integrity of SIS from families and individuals who will try to skew the results in order to acquire additional funding by falsely elevating support needs. And we note, pointedly, that nowhere does this same report reference the conflict of interest inherent in government staff conducting assessments when they also determine funding. Families have more to fear from this conflict of interest and the power of government than government has to fear from families and individuals with developmental disabilities.

To the credit of SIS's developers and proponents, they never claim SIS results to be the sole measure in determining needs and certainly never the means of determining an individual's vision, goals, the means of determining those goals, who should be involved, how those goals should be achieved, in what environments and so forth. It may add information to these determinations but SIS results are not the arbitrating factor in the many facets of an individual's life. The challenge as yet unmet is how to ensure SIS's acknowledged limits are understood and considered so that it is not elevated to having impact over the course of someone's life, for example, by determining funding.

SIS proponents assert it can be used to provide for a more equitable distribution of government funding than is currently the case. And one of the reasons government has claimed it needs to use SIS is that it has not had consistent means to determine an equitable distribution of funds. In other words some people with similar needs receive different levels of funding. The problem with this claim is that this would be as true with SIS as it might be now. Individuals with similar needs are unique and lead unique lives with unique conditions, as is true for all of us. Second, SIS itself notes that it typically would only be one factor in determining funding. A categorical model of funding derived from or with SIS measures falsely implies those with the same SIS level all require the same funding. It is a fact that even within categorical funding models inequities persist and sometime to a greater degree particularly for those with the most significant disabilities. That is the most vulnerable individuals are likely to experience the greatest inequities.

How does SIS work as a means of determining funding? In essence the results of an individual's SIS are reduced typically to one of seven levels of support needs. These levels are based solely on the statistical distribution of the individual scores of all those assessed. This robs individuals for the totality of their being, complexity and individuality by reducing them to a singular number between 1 and 7. It categorizes our sons and daughters, our family members, in the same manner in which individuals with were once scientifically categorized as imbeciles, morons and idiots and later more politely those with mild, moderate, severe and profound disabilities. So while SIS claims to measure something different than what traditional IQ and adaptive tests measure, in the end there is no difference. Over and over again we have seen when individuals with developmental disabilities are reduced to a single number or category it threatens their well-being; it is a dangerous thing to do to vulnerable individuals struggling to be recognized as fully human and equally valued.

“Do not reduce my daughter to a number. Don't categorize her or rank her. She is first, foremost and always a person”.

This reduction of vulnerable individuals to a singular number, to a category and thus to categorical funding is dehumanizing. Even if a SIS level were to only one variable in a funding model, it would still mean having people with developmental disabilities reduced to singular number and a category of common perceived needs. All the evidence in the field of developmental disabilities has repeatedly demonstrated that deindividualization and its accompanying categorization leads to increased vulnerability and a marginalized existence, particularly for those with greater needs. Almost every example offered by the proponents of SIS illustrate this fact, as for example, those with more needs are often described as living in group homes while those with lower needs are seen to need to live in their own homes. When in truth those with more substantial support needs have the same fundamental human need to have a home of their own as anyone else. Proponents of SIS consistently reference that SIS supports and enables inclusion. AACL's review of the literature has not found this to be accurate particularly as achieving an inclusive life is beyond SIS's purpose or capacity. To say nothing of the thousands of individuals with developmental disabilities across the globe who are pursuing an inclusive life long before SIS existed or without ever having been subjected to SIS.

It is not possible to have a categorical model of funding and a system that claims to consider each and every person as an individual to be supported through a personalized plan. The risk to SIS being used in as a categorical means of funding was evident last spring when government documents became public that illustrated how the SIS levels could be used to address a funding shortfall of 40 plus million by placing individuals into one of seven levels and than simply cutting the funding to that category. And we are seeing it now in the arbitrary and non-transparent manner in which SIS levels are being used in some PDD regions.

The nature of a funding model is such that it will drive a system and if a system is to be truly reflective of an individualized and personalized approach to supporting people than its funding model needs to individualized and personalized, not categorical.

The use of a SIS singular number in defining an individual's funding is no different than using an IQ score to determine an individual's needs or eligibility. Psychologists are required by their professional ethics to not make determinations or recommendations with respect to an individual's needs on the basis of a singular score, such as an IQ score. Psychologists are requires to take the entire individual into account. This is why the courts have ruled that PDD's reliance on a singular IQ score, which requires a psychologist to determine, is not a valid means of determining PDD eligibility. Similarly, the Psychology Association of Alberta, in a well written position paper, recommended to Alberta Education that it should stop the multi-million dollar costs of assessing children with special needs for funding purposes and focus on addressing needs to which psychologists would much prefer to dedicate their expertise and knowledge.

Interestingly enough, while Alberta Education has ended its categorical model of funding, another government department, Alberta Human Services, has not ruled out instituting the same failed approach. Many families are under the false impression that if SIS determined funding, than the funding would be attached to their family member. As with Alberta Education whatever the funding accorded an individual child, it is actually part of the total funds that flows to a school district. Similarly, whatever funding model might exist based on SIS it would still result in funds flowing in total to an agency (for those receiving supports for an agency) and in turn that agency

would be and necessarily must be responsible for the allocation of the funds it receives to the best interests of everyone it supports. Given approximately 85% of individuals with developmental disabilities are served by agencies, a SIS funding model would only alter how much money an agency receives in total not what an individual receives by way of support from an agency or how that support is provided. Changing what supports need to be provided and how requires other means. And we suspect, as was the case with Alberta Education and school districts, if service provider funding is tied to SIS levels than service providers will strive to obtain higher levels in order to increase funding. This is the natural order of the world.

First Recommendation

AACL recommends the Alberta government demonstrate its deep respect for the inherent uniqueness and humanity of each individual with developmental disabilities by stipulating that SIS levels will not be attached to any individual and no funding model or resource allocation will be attached to or based on SIS levels.

2) SIS as a requirement and a source of information:

a) We have no doubt the SIS process can be improved although we are not sure what this would mean to the statistical properties of SIS that so endear it to researchers and government officials. The current requirement that everyone be subjected to the same SIS questions no matter how applicable or invasive is a form of mortification and deindividualization. No other circumstances exist where anyone in need of services and supports must answer a host of questions for hours irrespective of the relevance of those questions to the service requested or need to be addressed. This is only done to those who are vulnerable and marginalized as it would be obvious this should not and cannot be done to ordinary Albertans. It would not be tolerated and would not even be considered. Non-disabled Albertans would find the process degrading at worst and at the very least, given the societal devaluation that exists for people with developmental disabilities, our government should do everything in its power to avoid processes that do not show sufficient individual respect for individuals with disabilities, who through no fault of their own, must rely to some degree on government support.

The reason the same questions are asked of everyone is that SIS requires it in order to compare the needs of one individual with all other assessed individuals. When an individual receives their SIS profile it illustrates, according to SIS, which life domains require more support than others and where the person falls in relation to others. That is, it compares the individual being assessed to all other assessed individuals in terms of how many more individuals have lesser or greater needs.

“Please don’t ask me questions you already know the answer to and have nothing to do with what I need”.

If this ranking of individuals relative to others were abandoned than SIS could be better tailored for individual circumstances and the threats inherent in ranking individuals relative to one another

removed. For example, person centered planning approaches do not require any relative ranking of one person to another.

Second Recommendation

AACL recommends that if SIS continues to be used only those questions from SIS that relate to the needs being considered, and to which individuals are prepared to answer, should be asked.

b) Lastly, is the question of the value of SIS in the information it provides relative to its costs in time, and in actual and hidden costs. As previously noted the proponents of SIS state unequivocally the SIS profile is only one additional source of information and its proper use requires all the features of person centered planning to be brought to bear. A SIS profile alone is completely insufficient for developing a person centered plan replete with a vision, outcomes, means and responsibilities. A position we think the government understands by virtue of its desire for every person to have an individual plan. However, a comparable investment to what has been placed in SIS has not been made in the development and implementation of individual person centered plans. An investment AACL believes would have been and could be far more beneficial.

Thus the question remains as to the difference SIS makes and the difference it makes relative to its associated costs. There is no empirical evidence, and the concept of empirical evidence is used here as the proponents of SIS claim the tool is based on empirical evidence, that a SIS profile makes a substantive difference and particularly on the scale to which it is being applied. There is no evidence that using SIS has improved the lives of the thousands on which it has been used. SIS, again as its proponents acknowledge, cannot tell you what job or career an individual with developmental disabilities should be considering, how they might acquire that job and until knowing the job and natural supports available what paid supports might be needed and how they should be delivered. And the same would be true for most if not all other aspects of a meaningful life. Often SIS asks for people to imagine, in very general ways, to guess their support needs in contexts they have never experienced.

SIS will not result in more individuals with developmental disabilities being employed or included in any other aspect of community life. It might give information about someone's support needs but typically in only the most general of ways. The published examples used by the proponents of SIS to demonstrate its utility, in AACL's view, are simplistic and ordinary, bordering on the banal. Far more proven, creative and innovative means exist and have been used for decades in meeting the needs of individuals with developmental disabilities to enable meaningful and inclusive lives in community. AACL's concerns with SIS were noted as far back as 7 years ago, including those of at least half the service providers consulted by government funded researchers- hardly grounds for proceeding unilaterally.

There are researchers in the developmental disabilities field attempting to create a SIS for children with disabilities. With the merger of PDD and FSCD there are risks and benefits. Clearly, a benefit is the future development of a service system that is seamless from childhood to adulthood. A risk, however, in the interest of creating a more unified system across ages, is that

system and bureaucratic needs prevail with SIS being imposed on children. AACL's hope would be that government not require every family of a child with disabilities to submit to an unproven and intrusive assessment. This time we would hope for meaningful consultation and an openness that allows for a critical examination of how to best determine needs, funding and the means of meeting needs.

The value SIS adds to determining supports within a comprehensive person centered planning approach is at best unknown and in AACL's view extremely limited. If the same investment in SIS was coupled with what is already known in enabling good lives, many more individuals with developmental disabilities would likely be living better lives today rather than having a SIS profile on their file and waiting for their profile to somehow materialize into action.

Third Recommendation

AACL recommends SIS be used selectively; it should be a choice offered individuals and families, not a requirement.

Conclusion

PDD proclaims it values families, individuals and the service sector with a desire to work collaboratively. We share this view and hold PDD in similar regard. It's time to eliminate the potential threat of SIS as a categorical and dehumanizing funding model, reduce the imposition of SIS, tailor it to individuals and test where and how it might be of benefit as an additional source of information in planning relative to its costs.