

## **Meeting Health Support Needs of People with IDD in Nebraska**

### **Community: New Initiatives and Future Directions**

*Nabih Ramadan, MD, MBA, and Christy Nielsen, MSN, RN*

*Nebraska Department of Health and Human Services*

*Division of Developmental Disabilities*

*Key words:* Intellectual disability; developmental disability; community health; health screens; health risk; evidence-base; developmental disabilities; nursing; comorbidity.

*Word count:*

Abstract= 497

Report= 5,766

*References:* 32

*Tables and figures:*

Tables= 6

Figures= 11

*Address correspondence:*

Nabih M. Ramadan, MD, MBA

301 Centennial Mall Drive, Third Floor

P.O. Box 98947

Lincoln, NE 68509

Telephone number: 402-471-9230

Fax number: 402-471-8792

E-mail address: [Nabih.ramadan@nebraska.gov](mailto:Nabih.ramadan@nebraska.gov)

**EXECUTIVE SUMMARY****Abstract**

*Background:* Health supports for individuals with intellectual and developmental disabilities (IDD) that transition from State-operated institutions into the community are critical. Identifying potential gaps between health needs and available resources are essential for optimizing support.

*Methods:* Medical case reviews (MCR) were conducted on people with IDD who transitioned from Beatrice State Developmental Center (BSDC- a Nebraska State-operated facility) into the NE community. Cases were selected based on health risk priorities. MCRs included systematic collection of information from records, face-face interviews with support staff (e.g., nurses, qualified intellectual disability professionals) and completion of general health, gait and balance, and physical nutritional risk screens. Demographics, intellectual disability (ID) levels, co-morbidities, health risk scores, residence type, nursing support levels and daily funding rates [for individuals who are not supported in community Intermediate Care Facilities (ICF) or Skilled Nursing Facilities(SNF)] were statistically-analyzed.

*Results:* Sixty individuals' MCRs (mean age  $\pm$  standard deviation= 55.6  $\pm$  12.2 y; 60% males; 85% with severe/profound ID) were completed June-September, 2012. Forty (66.7%) did not live in ICFs or SNFs ( $p > 0.1$  for demographic distribution and comorbidity comparisons with the total group). 90% (54/60) had  $\geq 3$  comorbidities. Constipation, epilepsy, gastro-esophageal reflux disease, and non-ambulatory status occurred in  $>50\%$ . Approximately 47% had a dual

diagnosis and/or were overweight. The majority of individuals scored high on  $\geq 1$  health risk screen and one-half scored high on all three screens. 36/60 (60%) had specific health support programs but none included all the necessary elements. Nursing support levels trended positively with the combined health risk scores ( $r= 0.21$ ,  $p=0.19$ ) and general health risk scores ( $r= 0.36$ ;  $0.01 < p < 0.05$ ). There was no relationship between dual diagnosis and nursing support levels ( $\text{chi-square}= 0.33$ ;  $p= 0.57$ ). Daily rates highly correlated with nursing support levels ( $r= 0.70$ ;  $p < 0.01$ ) but not with overall health risk scores ( $r= 0.10$ ;  $p= 0.56$ ). Qualitatively, the majority receives appropriate primary care services but we found inconsistencies and gaps in illness prevention and early recognition practices, follow up on laboratory testing, and timely referrals to specialists. Also, there were significant gaps in community capacity for integrated specialty care (e.g., behavioral health and psychiatry, physical nutritional services, gait and balance) and in community-medical providers' communication of health information. Ongoing competency-based training on commonly encountered conditions such as emergency response to prolonged seizures, pain evaluation, functional behavioral communications, nutritional support, and therapeutic positioning was missing.

*Conclusions:* This program was a pilot and included a relatively small number of people with IDD. Notwithstanding, we unraveled systemic strengths (commitment, dedication) and challenges (high medical needs, nursing levels, medical community capacity, funding) when aiming to provide evidence-based, person-centered and integrated health support for individuals with IDD who have

complex medical problems. All are manageable through enhanced training, standardization of health support practices and guidelines, private-public collaborations, allocation of funding for health support based on specific individual's medical needs, regular monitoring, and continuous quality improvement. The program could be expanded locally and nationwide in order to arrive at universal recommendations that are generalizable to all people with IDD.

**TECHNICAL REPORT****Background**

The last four decades have witnessed a substantial shift in residence of people with intellectual and developmental disabilities (IDD).<sup>1,2</sup> Institutional beds in the United States have declined in number by more than 200% during this era, from approximately 200,000 in the 1960's to less than 50,000 three decades later.<sup>1</sup> Today, the majority of people with IDD lives in integrated settings in the community and is supported locally.

Individuals with IDD have several physical, mental and medical comorbidities that often require intense support.<sup>3-10</sup> Among others, regular primary care provision, appropriate referrals to specialists, integration of allied health services into overall care delivery, nursing services, optimal allocation of human and financial resources, and ongoing competency-based training all are critical in providing medical support that should match the individuals' needs.

Migration from institutional living into the community,<sup>1,2</sup> increasing prevalence,<sup>11</sup> aging,<sup>12</sup> and the often complex nature of their medical conditions<sup>3-10</sup> all necessitate enhanced residential, vocational, and medical supports to meet the needs of people with IDD and assist them in leading a productive, healthy and safe life. These ever-challenging tasks are recognized statewide and nationally, and have resulted in focused efforts to create, improve and sustain support networks in the community for people with IDD. Nebraska and other states are responding to these challenges by developing, implementing and monitoring programs that assist individuals with IDD successfully transition out of

institutional settings (e.g., State-operated Intermediate Care Facilities- ICF). Indeed, over the last five years, the census at Beatrice State Developmental Center, a Nebraska-operated ICF has declined by approximately 60% to its current census of 136. In addition, Nebraska continues to solidify its systems of medical assistance, oversight, and quality improvement for people with IDD who left BSDC. Finally, Nebraska and many other states are under decrees from the federal government to improve health and residential support networks for people with IDD, at the ICFs and in the community equally.

Over the last several months, the Community-Based Medical Services Team of the Nebraska Department of Health and Human Services, Division of Developmental Disabilities (NE-DHHS-DDD) conducted several medical case reviews on people with IDD who reside in the community. The objectives of these efforts were to (1) conduct comprehensive analyses of health needs and provided supports; (2) determine strengths and challenges in providing optimal health support to the individuals in the cohort; (3) evaluate the relationship between health support needs and level of funding; and (4) develop recommendations for improved and sustained health support practices.

### **Methods**

Medical case reviews were conducted in several phases: (1) reviews of records available on the NE-DHHS-DDD electronic server; (2) reviews of records available at the residential sites; (3) reviews of records submitted from external health entities such as hospitals and medical clinics; (4) in person interviews with members of the individual's support team; (5) observations, and limited

examination –by one of the authors (NR)- of individuals at their homes and/or vocational sites; and (6) reviews of additional records that were requested during the face-face interviews. Ascertainment of medical diagnoses was made from records, interviews with nursing staff, and diagnostic (laboratory, radiological) and medication records.

Inclusion criteria for case review were: (1) 2011 high health risk scores on any of three health risk screens [General Health Risk (HRS), 25 items; Spine and Gait Risk (SGS), 27 items; Physical and Nutritional Management Risk (PNMS), 40 items]; (2) geographic proximity to people with high health risk scores; and (3) special request from individuals' community coordinator specialists (CCS).

Year-2012 health risk screens were completed on site or by telephone (n= 2) by the authors through direct interview with nursing and/or residential managers.

Health support needs were judged based on the overall health risks, which were derived from the three health risk scores.<sup>13-15</sup> For HRS, the range of score for low (1) is <11.69, moderate (2)= 11.69-26.19 and high (3) is >26.9. Ranges of scores for SGS are: low (1) <9.53; moderate (2)= 9.53-27.45; high (3) >27.45. Lastly, ranges of scores for PNMS are: low (1) <9.00; moderate (2)= 9.00-28.11; high (3) >28.11. SGS was designed for individuals who are ambulatory and therefore screens were not completed for individuals who could not ambulate for the majority of the time. These individuals were assigned a high categorical score (3) on SGS. Similarly, PNMS was designed for individuals who are able to eat by

mouth. Therefore, PNMS screens were not completed for individuals whose nutritional support is enteral; they were assigned a high categorical score (3).

Overall health risk scores represent the arithmetic sum of each individual's categorical health risk score and ranged from 3 (low on each of the health risk screens) to 9 (high on all screens). Ranking of health priority was based on the overall health risk scores.

One of the intents for the medical case reviews was to assess nursing levels of support in the community. Therefore, nursing supports in skilled nursing facilities (SNF) and ICFs were excluded from the nursing support level analysis. Accordingly, we assigned nursing level support scores of 1, when nursing availability was periodic on site and when needed after hours, 2 when nursing support was available on site daily but not 24h per day, and 3 for 24h on-site nursing support –Medical Service or Support Unit (MSU).

Follow up on medical case reviews are being conducted as follows: (1) CCS and individual's support team discussion of reports and recommendations generated; (2) Face-face special team meetings with the authors to ascertain the accuracy of information in the reports and to provide a forum for discussion on, and clarification of the recommendations; (3) guardians' informed consent to discuss the case reviews with the individuals' medical providers; (4) implementation of agreed upon recommendations that do not require approval from the community medical providers; and (5) meetings (in person or telephonically) between medical providers and one or both authors to discuss the case reviews and to pursue agreed upon recommendations.

Funding data were obtained for individuals who are not supported in ICFs or SNFs. To this end, NE-DHHS-DDD allocates funding resources for people with IDD who are supported by the Division, on the basis of a rate-methodology that derives from ICAP (The Inventory for Client and Agency Planning) scores,<sup>16</sup> which is proven superior to levels of intellectual disability when assessing support needs for individuals with IDD.

Qualitative data were collected systematically by one or both authors and summarized in the reports generated. Quantitative data were entered by one of the authors (NR) on excel spreadsheets. Data entry was checked against paper source data by the same author. Descriptive statistics were used to determine means, standard deviations, and distribution patterns. Comparative statistics (t-test, analysis-of-variance, regression analyses, chi-square test, and correlations as appropriate) were used to (1) compare 2011 vs. 2012 data; (2) assess relations between the three health scores; (3) evaluate relationships between nursing level of support and acuity of medical needs; and (4) analyze funding for individuals who receive payments that are not ICF or SNF-recovered.

Level of statistical significance was set at 0.05 for single analyses, and at <0.01 when multiple analyses were conducted on like variables in order to minimize false positives.

The project was part of the day-to-day activities of the NE-DHHS-DDD, Community Based Services, and is not an experimental study. Therefore, no Institutional Review Board application or approval was required.

## **Results**

### *Demographics*

Sixty-nine individuals met entry criteria for case review; nine guardians declined our review. Medical reviews were conducted by the authors on the remaining 60 individuals with IDD between June and September, 2012. Age and gender distributions are represented in Table 1.

Five of the 60 individuals lived in SNFs, sixteen lived in MSUs, fifteen were in ICFs, six were in group homes with 8h face-face nursing, and the remaining 18 lived in group homes or extended family homes where nursing support is available when needed. The mean age for the forty individuals who reside in community settings that are not ICFs or SNFs was 54.5 y (standard deviation= 15.3; age range= 27 to 90 y) and the male-to-female ratio was 26:14 (65% males).

### *Level of intellectual disability and co-morbid medical conditions*

The overwhelming majority of the 60 individuals whose cases were reviewed had severe or profound intellectual disability (ID), based on Intellectual Quotient (IQ) testing (Table 2). In addition, all had at least one comorbid condition and 90% had three or more associated medical illnesses. More than 50% of the individuals had constipation, epilepsy, gastro-esophageal reflux disease (GERD), and/or were non-ambulatory; approximately 50% had a dual diagnosis (IDD and Axis I diagnosis) and/or were overweight. Lastly, it is noteworthy that close to 30% of the individuals were receiving nutritional support through enteral means (gastrostomy or gastro-jujenostomy).

### *Primary care services*

Annual physical examinations were conducted on all individuals prior to their annual Individual Program Plan (IPP) meetings. Depending on the residential setting, individuals were accompanied to their medical visits by nursing staff, direct support staff and/or residential managers. Diverse forms accompanied the individuals to their visits. Such forms included, among others, referral reports and medication administration history. Only a few included comprehensive summaries of interim events that were completed by nurses. Inconsistently, medical observation logs or summaries accompanied the individuals to the medical visits.

Physical examinations were conducted by primary medical providers (physicians or physician extenders such as physician assistants and nurse practitioners). Records of the annual visits were sketchy with a few exceptions. In addition, recommended standards for early illness recognition, wellness, and illness prevention, were inconsistent. Vaccination recommendations were followed by the overwhelming majority with a few exceptions. Recommended laboratory and diagnostic studies (e.g., mammography, Pap-smear, therapeutic and diagnostic drug periodic monitoring) were obtained on the majority, although not on all. Documentation of results and follow up on abnormal results were inconsistent.

#### *Specialty care services*

Referrals to medical specialists, at the request of the primary care providers, were generally appropriate; delays were noted. Evidence of communication between primary care providers and specialists were not found regularly.

Thirty-six individuals (60%) were deemed candidates for specialized, integrated physical and nutritional support services because of medical conditions such as enteral nutrition, repeated history of aspiration pneumonia, overweight in association with physical impairment, nutritional difficulties associated with mental and/or behavioral problems, etc. At the time of the case reviews, only four of these individuals ( $4/36= 11\%$ ) had received such services.

Fifteen individuals (25%) were judged to be candidates for specialized gait and balance clinic evaluation and management for conditions such as frequent falls, gait instability, progressive gait impairment, musculoskeletal deformities causing posture and gait problems, etc. Thus far, none had participated in such specialty consultation.

Collaborative practices notably were missing between behavioral health practitioners and psychiatrists, and between psychiatrists and neurologists who prescribe medications with overlapping indications. Furthermore, most behavioral support plans (BSP) were developed generically without in depth functional behavioral assessments (FBA). To this end, FBAs were developed by human services professionals with limited expertise in applied behavior analysis. Also, behavioral data were collected inconsistently. Lastly, when shared with the therapist or the psychiatrist –not consistently, information were represented in numbers or percentages, which is difficult to quickly interpret in an office visit, and not analyzed prior to evaluation by the specialist.

We observed that several teams struggled with pain assessment, approaches to pain measurements were inconsistent, particularly for people who

cannot express themselves verbally, and some tools used were not appropriate for the particular individual (e.g., PAINAD or Pain Assessment in Alzheimer's Disease).

### *Health screens*

More than 50% of the 60 individuals whose cases were reviewed had a high score on one or more of the individual health risk screens (Table 3). Forty-seven individuals (78%) scored high on at least one of the three screens and 30 (50%) scored high on all. Furthermore, the distribution of scores was rightward shifted (negative skewness). In other words, more scores are higher than the mean score. Lastly, it was noted that the overall risk for the cohort is 7.70 with a median of 8.50, which indicates that the majority of individuals has high overall health risks. These results are concordant with data from (a) Table 1 showing a relatively older cohort, and (b) Table 2 indicating that 90% of individuals have three or more comorbid medical illnesses.

Eight of the 30 individuals who scored high on all screens (27%) live in residential settings where nursing services are provided only when needed; seven additional individuals have at least one high health risk score and live in similar settings. On the other hand, nine of the 60 individuals (15%) were supported in residential settings where on-site nursing is available daily (nursing level 2), yet none had a high overall health risk score (overall risk score  $\leq 6$ ).

It should be noted that HRS categorical scores were highly predictive of SGS ( $r = 0.581$ ;  $p < 0.01$ ) and PNMS categorical scores ( $r = 0.718$ ;  $p < 0.01$ ). Also,

advancing age correlated with HRS continuous scores (Figure 1), although the significance was not as pronounced ( $r= 0.293$ ;  $p= 0.02$ ).

Comparisons of 2012 to 2011 medical risk scores are depicted in Figure 2. As shown, there was a significant worsening in HRS for individuals who had data recorded during both years. Similar, albeit not as significant, worsening of PNMS was noted. In contrast, there was a non-significant improvement in SGS.

Separate analyses were conducted on individuals ( $N= 40$ ) who were not supported in ICFs or SNFs. They have similar demographic distribution (mean age  $\pm$  SD=  $54.5 \pm 13.3$ ; M:F= 26:14), ID levels, and medical conditions (Table 4) to those of the larger cohort ( $N= 60$ ) (pairwise t-tests; all p-values  $>0.1$ , individual p-values not shown).

Similar to the total group, health support needs of these 40 individuals, as reflected in the individual and overall health screen scores (Table 5) and their comorbid conditions, were intense (mean overall risk for the group= 7.48; median= 8). Also, their overall risk score distribution was negatively-skewed (Figure 3); none scored low on all three screens, twenty-eight (70%) had 7-9 scores, and 19 (47.5%) scored high on all screens.

#### *Nursing support*

Health support plans were available on 36 of the 60 individuals whose cases were reviewed (60.0 %). Some were identified under a "Safety Plan", some were included in the Health support section of the IPP, and others were identified as nursing care plans. Only two were comprehensive and included details of medical diagnoses, health or nursing needs and implementation strategies.

However, none clearly identified realistic goals, timelines, and assigned responsibilities. In addition, when health support plans represented nursing plans, they were used for communication among nurses instead of tools for staff to train on and implement.

Nursing support level scores for individuals who do not live in SNFs or ICFs (Table 5) were normally distributed (Figure 4), in contrast with the overall health risks for this cohort (Figure 3). These results indicate a potential mismatch between overall health risk scores and nursing levels of support. In other words, fewer individuals with higher health needs are supported by higher nursing levels than is expected.

In order to better delineate the relationship between nursing level of support and overall health risk scores, a regression analysis was conducted. The analysis indicated a non-significant trend ( $r= 0.21$ ;  $p=0.19$ ) in the right direction, i.e. higher risks are matched with higher level of nursing support (Figure 5; green trend line). The lack of a robust positive correlation likely is related to several outliers in the sample (figure 5, arrows), and potentially because of a small sample size. For example, two individuals are supported by level 3 nursing (high) when their overall health risk scores are moderate (5,6) (Figure 5, red arrows). On the other hand, three individuals are supported in a level 1 nursing setting while their overall health risk scores are high (7,8,9) (Figure 5, blue arrows).

Further exploratory analyses were conducted on the relationship between nursing levels and health scores (Figure 6), and nursing levels and priority rank (Figure 7) for people who are not supported in ICFs or SNFs. Since HRS scores

predict SGS and PNMS scores, we used the HRS continuous scores to assess correlation with the nursing levels of support (Figure 6). The correlation trended positively (Figure 6, green line) and better than the nursing level vs. overall risk scores, but here again the correlation coefficient  $r$  and the  $p$ -value were not statistically robust ( $r= 0.36$ ;  $0.01 < p < 0.05$ ).

Similar to the relationship between HRS and nursing level, there was a right trend (Figure 7, green line) for nursing level and priority ranking, i.e. higher rank or lower overall risk corresponds to a lower level of nursing but the correlation was not significantly robust ( $r= 0.36$ ;  $0.01 < p < 0.05$ ).

Finally, and in order to evaluate a potential effect of dual diagnosis on nursing support level, analysis of interdependence was conducted using chi-square contingency (Table 6); no significant relationship exists (chi-square= 0.33;  $p= 0.57$ ).

### *Training*

General and individual needs-specific training were offered (we did not observe any group or individual training but reviewed training curricula, when available). Basic aid, cardiopulmonary resuscitation, and medication aides training were appropriate. Some providers provided training on specific conditions such as epilepsy. Notable training deficiencies were in (1) medication side effects; (2) appropriate delegation of nursing services; (3) functional communication and interfering behaviors; (4) case-specific therapeutic positioning; (5) pain assessment; (5) emergency medical responses; and (6) diet preparations. Furthermore, ongoing knowledge and skills-based competency training and

evaluation were not applied consistently. In some instances, training attendance was used as proof of training, which is not desirable.

### *Daily rates*

As indicated under the background section, daily rates were assigned based on ICAP scores. Daily support rates for the individuals who are not in ICFs or SNFs varied between \$142.50 and \$690.00 (Table 7).

As anticipated, daily rates highly correlated with levels of nursing support ( $r= 0.70$ ;  $p< 0.01$ ) (Figure 8). However, it should be noted that two significant outliers existed at the lower end of the nursing support level (level 1) (red arrows, Figure 8). These individuals are receiving \$508.96 and \$690.00 per day. One outlier is noted at nursing level 2 (blue arrow, Figure 8); this individual is receiving \$206.23 per day.

Similar to the overall risk scores, the distribution of daily rates was negatively skewed (Table 7 and Figure 9) but the degree of skewness (-0.55) was not as pronounced as that of the overall health risks for individuals who are not in SNFs or ICFs (-0.79; Figure 3). This suggests some mismatch between overall health risks and funding based on daily rates for these individuals.

In order to further elucidate the relationship between levels of funding and overall health risk scores, a correlation analysis between these variables was conducted (Figure 10). As can be seen, there was no correlation between level of funding and overall health risk scores ( $r= 0.10$ ;  $p= 0.56$ ). Several outliers contributed to the lack of a true relationship, particularly at the upper end of the overall health risk scores (dotted box, Figure 10).

Finally, we conducted a regression analysis of daily rates and presence/absence of dual diagnosis (Figure 11); no significant relationship was found ( $r= 0.074$ ;  $p= 0.64$ ).

#### *Follow up on case reviews*

To date, seven guardians (six are guardians for individuals in SNFs) have declined any further involvement by the Community-based medical review team in the oversight of health support for their wards. Community coordinator specialists held inter-disciplinary team meetings on all individuals between July and October, 2012 in order to discuss initial impressions of reports and, when applicable, pursue some agreed-upon recommendations. Furthermore, thirty-two face-face special IDT meetings were conducted between the authors and the individuals' teams between October 15<sup>th</sup> and November 15<sup>th</sup>, 2012.

The face-face interviews have proven very valuable in discussing the reports and clarifying stated recommendations. In particular, on-site training was provided on the value of establishing comprehensive health plans and health observation logs, limited community capacity for integrated physical nutritional consultations or specialized gait and balance clinic were circumvented by using a roadmap to enhance inter-professional communications, various standardized screening, referral, monitoring, and data summary tools were shared, and on-site training was conducted on means of summarizing observational data (e.g., weights, interfering behaviors, seizure counts, etc.). It should be noted that initial skepticism about, and significant resistance to using integrated health plans have

yielded to a better understanding of their value and critical role in optimizing the health support of people with IDD.

Face-face discussions with the medical providers are now planned as guardians' signed informed consents are received.

## **Discussion**

Migration of people with IDD from institutions into inclusive community settings requires significant health, vocational and recreational resources (e.g., infrastructural, human, and funding) to meet the needs of people in their new environment. Determining optimal resources need cannot be accomplished without conducting gap analyses that assess these needs and match them with commensurate support. This first and innovative community-based program, which was conducted by the NE-DHHS-DDD's medical team represents such an analysis, and shows significant promise in elucidating strengths and challenges in supporting the health and wellbeing of people with IDD who receive State funding.

The initial case reviews identified the commitment of community providers in supporting people with IDD. Also, we noted the willingness of Developmental Disabilities (DD) providers' administration and support staff to learn and implement strategies that optimize health services delivery to people with IDD. Furthermore, the case reviews helped to unravel gaps in provision of community health support, which could be bridged through collaborative and non-intrusive support from experienced and dedicated State teams such as the medical and CCS teams.

Face-face follow ups from the initial case reviews proved very useful in discussing with diverse team members and with guardians the value of focused medical reviews that could lead to optimal health support. To this end, the initial reviews and the follow up meetings led to endorsement of some recommendations by the medical community and the community providers. These have included, among others, (1) revisiting need for continuous enteral feeding, medical response to seizures, anti-epileptic polypharmacy, ongoing use of benzodiazepines for mental illness, and psychotropic polypharmacy; (2) implementation of consistent standards of illness prevention and early detection strategies (e.g., vaccination, cancer screens, etc.); (3) focus on therapeutic, judicial and indicated therapeutic drug withdrawals for people with well controlled epilepsy; (4) re-initiation of restorative care programs for people with positioning problems; (5) specialty medical referrals; (6) referrals to medical nutritional therapists for weight management; (7) development of integrated health support plans that address realistic goals and timelines; (8) enactment of safe position to mitigate choking and aspiration in people at risk; (9) integration of standardized pain assessment tools into health services support; and (10) adoption of BSDC-developed programs for physical and nutritional support that focus on integrated support, comprehensive points-of-service implementation strategies, direct and indirect allied health therapies, and competency-based support staff training.

It would be presumptive to assume that all recommendations offered in the case reviews will be embraced since evidence-based health practices are not one-size fits all and health providers incorporate best practice with experience to

support the health needs of the individual with IDD. Also, the authors acknowledge that peer-reviews are not always welcome, particularly when coming from governmental bodies. However, these potential barriers are not insurmountable. Enhanced communication between States' medical/nursing personnel and the community medical providers, delineation of the roles and responsibilities of the medical review team in community-based services policies and procedures, establishing minimum yet comprehensive requirements for annual physical examination<sup>3</sup> (e.g., standardized forms and check lists such as the Massachusetts Health Quality Partners checklist,<sup>17</sup> which include early illness recognition, preventive measures, cancer screen, etc.), consistent reminders – from the CCS's to the teams and guardians- of the availability of the medical team to assist and support are some avenues that could lead to an optimal and collaborative relationship between the community and the States' divisions of IDD. Above all, improved individuals' health outcomes that can be, at least in part, related to the afore-described medical and CCS team efforts remain the strongest driver to full collaboration.

The cohort reviewed indicated the significant challenges in supporting the health of people with IDD. As was evidenced from the results, 90% of people whose cases were reviewed had three or more co-morbid medical problems and approximately 50% had dual diagnoses. Furthermore, the high health risk scores are testimonial to the complexity of the individuals' health status. These findings stress the need for more comprehensive and integrated health services delivery for people with IDD.

Results from our reviews indicate that most people have constipation. Multiple factors could contribute to constipation in people with IDD including medications, physical inactivity and sedentary life style.<sup>18</sup> Diligent and ongoing review of medication regimens is essential in evaluating the potential contribution of prescribed –and over-the-counter- medications to constipation. Accordingly, changes in treatment strategies, when possible, could ameliorate the problem. Furthermore, encouraging physical exercise and daily activity are other helpful approaches that could be explored.

The cohort whose cases were reviewed, similar to people with IDD in general,<sup>7-10,19</sup> has a high prevalence of overweight, non-ambulation, and osteoporosis. Dietary habits, physical limitations, imbalance in essential nutrients such as vitamin D and calcium, physical inactivity, and sedentary life style all are likely contributors to such high prevalence rates. They can be managed through, among other interventions, (1) encouraging physical exercise and activity; (2) optimal nutrition, and (3) nutritional supplements when indicated.

Case reviews and direct interviews and follow ups pointed to the difficulties teams face when assessing individuals with pain who cannot express themselves verbally and whose interfering behaviors could be symptoms of pain. We conducted initial training on the Pain and Discomfort Scale (PADS)<sup>20</sup> and advised teams to conduct specific and rigorous functional behavioral analysis observations that could assist support staff in differentiating between pain-related behaviors and other interfering behaviors.

Behavioral support plans were noted to be deficient. Enhanced training and modeling of FBA and BSP, standardization of data capture and data summary, and consistently sharing information with therapists and psychiatrists equally are steps in the right direction.

Capturing health (e.g., sleep pattern, weight, etc.) and mental illness observations through diaries or logs are key components of health support and management.<sup>21</sup> People without IDD are constantly reminded to assume ownership in their own health management.<sup>22</sup> Individuals with IDD are no exception and should fully participate in their health management to the extent possible, either directly or through proxy (staff support). The noted incomplete and often inconsistent symptom and health observation capture systems across DD providers are a hindrance to proper health management, but the problem can be addressed through (1) a-priori discussion of expectations re: health tracking forms with community providers; (2) discussion with medical providers of desired information; (3) summaries of interim medical histories by nurses, when available; and when possible (4) standardization of health tracking forms across DD providers; this would improve support, oversight, and quality assessment and improvement.

Prioritization of health risk arguably is valuable in (1) determining funding and human resource needs, and (2) accordingly allocating resources when they are not limitless. The use of the three health screens used in the reviews is showing promise in strategizing CCS frequency of visits to individuals with IDD, and the focus of the visits. Also, it is worth noting that the 2012 HRS and PNMS

screens were significantly worse than the prior year. We have not conducted any in depth analysis of potential reasons and any assumption is hypothetical.

Nonetheless, analysis of factors contributing to such changes is important in proper health support planning. Also, recognizing the worsening in population scores could assist in better allocation of resources.

The results indicate that nursing support could be improved by better matching individuals' health needs with nursing levels. As indicated in the results section, we have uncovered some nursing levels that arguably are higher than what the individuals might need. Conversely, we found that some individuals have high medical needs and yet their nursing support level is not commensurate. A few recommendations could be entertained to rectify this mismatch: (1) re-assign nursing support on the basis of overall health risks; (2) incorporate full discussions of overall health risks in initial and ongoing plans of transition from state-run ICFs into more inclusive community-based settings; (3) develop explicit guidelines of nursing level support that community providers adhere to; and (4) allocate funding for health support on the basis of overall health risk scores.

Nursing level (number of hours) is one factor in improving health support for people with IDD. In addition to a better match of nursing support level and other obvious factors such as qualified nursing, and nurse training on medical issues in people with IDD, health needs could be better met with improved and standardized health support plans that become an integral part of the health supports program in the IPP. As stated earlier, the cohort whose cases were

reviewed has substantial health problems and the majority is assisted with medication administration. Both require nursing support and health plans that nurses could oversee or assist in developing.<sup>23</sup> As such, a-priori discussion of expectations re: health support plans with community providers could be conducted, and training and refresher courses could be planned.

During the follow ups, several teams sought clarification on specialty referrals, notably PNCS, Gait and Balance and behavioral health. Also, many welcomed the idea of the inter-disciplinary and the 'one-time-stop' approaches. As the results showed, many individuals could benefit from these referrals, yet the capacity in the community is limited. Some potential solutions to this gridlock are: (1) continual training on value of such referrals; (2) circumventing the misconception that these consultations have to always be conducted in person on an ongoing basis; (3) wide use of tele-health services that defy geography and distance; (4) increased provision of such services from clinics that currently conduct these special consultations (e.g., Beatrice State Developmental Center, Public Health Clinic, Munroe-Meyer Institute, Madonna Rehabilitation Institute, etc.); and (5) enhanced inter-professions communications through sharing goals, reviewing progress, and adapting universal forms such as points-of-service forms, which capture goals, outcomes, implementation or action plans, responsibilities, and others.

Capacity for specialty services other than PNCS or Gait and balance remains uneven in the Nebraska community, particularly with respect to psychiatric, psychological and neurological care. This problem is not unique to

Nebraska and could be improved through an enhanced system of tele-health between recipient primary care providers or midlevel providers and tele-specialists.<sup>24,25</sup>

Optimal support comes with proper, consistent, and recurring training of support staff. We observed that training in the community can be improved. This could be achieved through (1) clarification of universal training expectations; (2) provision of standardized competency-based (skills, knowledge, experiential) education; (3) ongoing course refreshers; (4) relevant and appropriate competency-based evaluations; and (5) continuing professionals' education on common medical problems in people with IDD, particularly with the recognition that training on IDD is minimal in health sciences colleges, nursing, dental and medical schools.<sup>26-29</sup>

Human resources go hand in hand with appropriate funding when supporting people with IDD. Our results showed no significant relationship between allocation of ICAP-derived daily rates and overall health support needs as measured by the overall health risk scores. Proponents of ICAP emphasize its wide use and acceptability across the United States and its desirable psychometric properties. ICAP has been validated in people with a dual diagnosis (almost 50% of the group in this report has a dual diagnosis),<sup>16</sup> but the paucity of its health-related items relative to the total items (n= 77) could have a negative impact on its generalizability for people with intense medical needs. Indeed, our results indicate that ICAP scores-derived daily rates do not correlate well with the health support needs of adult individuals with IDD and multiple

comorbidities. Furthermore, ICAP has been normalized for 0-50 year old individuals,<sup>30</sup> and people in this report and nationally are aging. Perhaps, ICAP is best used to allocate residential and vocational support funds for people with dual diagnoses and low health needs but more specific health screen tools should be used for allocating resources to people with IDD and significant medical co-morbidities. Alternatively, efforts could be placed into ICAP modifications and norming for individuals with high medical needs and those who are older than 50 years.

Results from this report should be interpreted with caution because of several limitations, and therefore could not be generalized to all people with IDD who live in the community. Notable limitations are: (1) the sample size included in the case reviews is relatively small (n= 60); (2) case reviews were not random; instead they were chosen on the basis of high health risks as judged from health risk screens and from impressions of CCSs. Indeed, individuals whose cases were reviewed represent a skewed population with high health needs as evidenced by the complexity of their medical problems and their level of ID. In general, and unlike the population in this report (85% have severe or profound ID), 85% of people with IDD nationwide have mild ID;<sup>31</sup> (3) the health risk screens have not been fully psychometrically tested for reliability and sensitivity; and (4) no formal assessment of outcomes has been analyzed to date because of the short follow up time since program inception.

The limitations afore-described are expected given the pilot nature of this program. In order to address the shortcomings, the project (1) could be

expanded to include a larger sample size and a more representative population of people with IDD; (2) further psychometric testing of the health risk screens would be required; and (3) outcomes should be collected and analyzed. Without such measures, it would be difficult to ensure sustainability and draw firm conclusions that are generalizable to all people with IDD who live in the community and are supported by state funds.

People with IDD will continue to move into more inclusive community-based setting; this is inevitable and healthy.<sup>1,2,19</sup> Arguing inevitability is an exercise in futility. This continuous movement likely will increase the currently recognized and nationwide disparity in health delivery for people with IDD.<sup>32</sup> Initiatives such as the one described in this report, development and implementation of similar programs that focus on behavioral health needs, managed care for people with IDD, and home health programs are steps to minimize the disparity and improve the lives of the IDD population. However, none could be optimized without collaborative and concerted efforts within a state and across states lines that focus on shared learning and best practices, establishment of state and inter-state research grants on health service delivery for people with IDD, and improved training at all levels including medical, nursing and allied health schools, residency programs, and social and human sciences colleges. This is a call to further action by all parties involved, the public, state government officials, the federal government, and academics equally.

**Acknowledgments**

The authors wish to thank the individuals with IDD who participated in this project, their guardians, all members of their support teams, and the Community Coordinator Specialists who support them. Also, we wish to acknowledge Ms. Carole Williams and Ms. Patti Bade for providing assistance with data entry and coordinating all our visits. Lastly, the authors wish to thank Director Fenner and Deputy Director Mason for their encouragement and support through the design and implementation of this project.

**Authors' contributions**

*Design of project:* Nabih Ramadan

*Data collection:* Nabih Ramadan and Christy Nielsen

*Data entry:* Nabih Ramadan, with assistance from Ms. Williams and Ms. Bade

*Data analyses:* Nabih Ramadan

*External statistical review:* None

*Initial draft of report:* Nabih Ramadan

*Review and finalization of report:* Nabih Ramadan and Christy Nielsen

**Conflict of Interest Statement**

Nabih Ramadan is on contract with NE-DHHS-DDD as the Division's Chief Medical Officer. Christy Nielsen is an employee of NE-DHHS-DDD.

**References**

1. Scott N, Lakin KC, Larson SA. The 40th anniversary of deinstitutionalization in the United States: decreasing state institutional populations, 1967-2007. *Intellect Dev Disabil* 2008;46:402-405.
2. Mansell J, Beadle-Brown J. Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *J Intellect Disabil Res* 2010;54:104-112.
3. Sullivan WF, Berg JM, Bradley E, et al. Primary Care of Adults with Developmental Disabilities. *Can Fam Physician* 2011;57:541-553.
4. de Winter CF, Jansen AA, Evenhuis HM. Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. *J Intellect Disabil Res* 2011;55:675-98.
5. Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental-ill health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psych* 2007;190:27-35.
6. Cooper SA, van der Speck R. Epidemiology of mental ill health in adults with intellectual disabilities. *Curr Opin Psychiatry* 2009;22:431-436.
7. Srikanth R, Cassidy G, Joiner C, Teeluckdharry S. Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities. *J Intellect Disabil Res* 2011;55:53-62.
8. Petrone LR. Osteoporosis in adults with intellectual disabilities. *South Med J* 2012;105:87-92.
9. Humphries K, Traci MA, Seekins T. Nutrition and adults with intellectual or developmental disabilities: Systematic literature review results. *Intellect Dev Disabil* 2009;47:163-185.
10. Stancliffe RJ, Laken KC, Larson S, et al. Overweight and obesity among adults with intellectual disabilities who use intellectual/developmental disability services in 20 U.S. States. *AJIDD* 2011;116:401-418.

11. Boyle CA, Boulet S, Schieve LA, et al. Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics* 2011;127:1034-1042.
12. Perkins EA, Moran JA. Aging adults with intellectual disabilities. *JAMA* 2010;304:91-92.
13. Ramadan N, Lenners J, Criner L, et al. Development and Implementation of a Health Risk Screen for Individuals with IDD. Poster presentation at the AAIDD 2012 Annual Conference, Charlotte, NC; June, 2012.
14. Lopez J, Edwardson R, Regier M, et al. Development and Implementation of a Spine and Gait Clinic. Poster presentation at the AAIDD 2012 Annual Conference, Charlotte, NC; June, 2012.
15. Lykins T, Regier M, Lopez J, et al. Development and Initial Implementation of a Physical Nutritional Support Program. Poster presentation at the AAIDD 2012 Annual Conference; Charlotte, NC, June, 2012.
16. Inventory for Client and Agency Planning (ICAP). Available at <http://icaptool.com/icap-accuracy/icap-content/>, last accessed 11.17.12
17. Massachusetts Health Quality Partners (2012). Available at [http://www.mhqp.org/guidelines/preventivePDF/MHQP%20Adult%20\(Rev.%2009-10\)%20copy12-3.pdf](http://www.mhqp.org/guidelines/preventivePDF/MHQP%20Adult%20(Rev.%2009-10)%20copy12-3.pdf), last accessed 11.17.12.
18. Martin D. Physical activity benefits and risks on the gastrointestinal system. Constipation and sedentary life style. *South Med J* 2011;104:831-837.
19. Martínez-Leal R, Salvador-Carulla L, Linehan C, et al. The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. *J Intellect Disabil Res* 2011;55:858-872.
20. PADS. Pain and Discomfort Scale. Bodfish JW et al. (2006). Issues in pain assessment for adults with severe to profound mental retardation. In F. Oberland & F.J. Symons (Eds.), *Pain in children and adults with developmental disabilities* (pp149-172). Baltimore: Brookes Publishing Company.

21. Lennox N, Taylor M, Rey-Conde T, Bain C, Boyle FM, Purdie DM. ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. *Health Promot Int* 2004;19:167-175.
22. Coulter A. Patient engagement--what works? *J Ambul Care Manage* 2012;35:80-9.
23. Gates B (editor). *Care Planning and Delivery in Intellectual Disability Nursing*. 2006 Blackwell Publishing Ltd, Oxford, UK:1-308. Available at <http://www.jazannurses.com/books/nursing/Care-Planning-and-Delivery-in-Intellectual-Disability-Nursing.pdf>, last accessed 11.17.12.
24. Hjelm NM. Benefits and drawbacks of telemedicine. *J Telemed Telecare* 2005;11:60-70.
25. Taber-Doughty T, Shurr J, Brewer J, Kubik S. Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities. *J Intellect Disabil Res* 2010;54:843-859.
26. Wilkinson J, Dreyfus D, Cerreto M, Bokhour B. "Sometimes I feel overwhelmed": educational needs of family physicians caring for people with intellectual disability. *Intellect Dev Disabil* 2012;50:243-250.
27. Woodard LJ, Havercamp SM, Zwygart KK, Perkins EA. An innovative clerkship module focused on patients with disabilities. *Acad Med* 2012;87:537-542.
28. Temple B, Mordoch E. Nursing student perceptions of disability and preparation to care for people with intellectual disabilities. *J Nurs Educ* 2012;51:407-410.
29. Krause M, Vainio L, Zwetchkenbaum S, Inglehart MR. Dental education about patients with special needs: a survey of U.S. and Canadian dental schools. *J Dent Educ* 2010;74:1179-1189.
30. Hill B. Adaptive and Maladaptive Behavior Scales (2001). Available at <http://www.assessmentpsychology.com/adaptivebehavior.htm>, last accessed 11.17.12.
31. King, BH, Toth KE, Hodapp RM, Dykens EM (2009). Intellectual disability. In BJ Sadock, VA Sadock, and P Ruiz (Eds.), *Comprehensive Textbook of*

Psychiatry (9th ed., pp. 3444–3474). Philadelphia: Lippincott Williams & Wilkins.

32. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev* 2006;12:70-82.

**Tables**Table 1. *Demographics of total cohort (N= 60).*

<b>Age</b>	
<i>Mean age ± SD (y)</i>	55.6±12.2
<i>Age range (min, max)</i>	27-90
<b>Gender (M:F)</b>	36:24

Table 2. *Medical conditions (total group).*

<b>Intellectual Disability (ID) level</b>	<b>N</b>	<b>%</b>
<i>Mild</i>	5	8.3%
<i>Moderate</i>	4	6.7%
<i>Severe/profound</i>	51	85.0%
<b>Co-morbid conditions</b>		
<i>None</i>	0	0.0%
<i>1-2</i>	6	10.0%
<i>3+</i>	54	90.0%
<b>Common medical conditions</b>		
<i>Constipation</i>	52	86.7%
<i>Gastro-esophageal reflux disease (GERD)</i>	39	65.0%
<i>Enteral feeding</i>	17	28.3%
<i>Diabetes mellitus</i>	6	10.0%
<i>Thyroid disease</i>	20	33.3%
<i>Osteoporosis</i>	26	43.3%
<i>Non-ambulatory</i>	35	58.3%
<i>Pneumonia in past year</i>	12	20.0%
<i>Epilepsy</i>	42	70.0%
<i>Dual diagnosis (ID + Axis I)</i>	28	46.7%
<b>Body Mass Index (BMI) abnormalities</b>		
<i>Mean BMI <math>\pm</math> SD</i>	25.42 $\pm$ 4.56	
<i>Overweight (BMI= 25+)</i>	28	46.7%
<i>Obese (BMI= 30+)</i>	9	15.0%
<i>Underweight (BMI&lt; 19)</i>	3	5.0%

Table 3. *Individual and overall health risk scores (total group; N= 60). Scores for SGS and PNMS were converted to the categorical scale (1-3) in order to account for non-numerical SGS and PNMS data (see text for details).*

	<i>HRS</i>		<i>SGS</i>	<i>PNMS</i>	<i>Overall risk</i>
	<i>Continuous</i>	<i>Categorical</i>			
Mean	32.23	2.57	2.58	2.55	7.70
Median	34.02	3.00	3.00	3.00	8.50
Standard deviation	13.18	0.65	0.67	0.59	1.63
Skewness	-0.22	-1.2251	-1.3584	-0.95022	-1.0011
Minimum	3.98	1	1	1	4
Maximum	58.96	3	3	3	9

*Note: 65.0% of the cohort scored high on HRS, 68.3% scored high on SGS and 60.0% scored high on PNMS*

Table 4. Medical conditions in people not in ICF or SNF (N= 40).

<b>Variable</b>	<b>N</b>	<b>%</b>	<b>Mean (SD)</b>
Intellectual Disability (ID) level			
<i>Mild</i>	4	10.0%	
<i>Moderate</i>	4	10.0%	
<i>Severe</i>	32	80.0%	
Body Mass Index (BMI)			24.8 (4.7)
<i>Overweight (BMI= 25+)</i>	18	45.0%	
<i>Obese (BMI= 30+)</i>	5	12.5%	
<i>Underweight (BMI&lt; 19)</i>	3	7.5%	
Constipation	34	85.00%	
Enteral feeding	13	32.5%	
Gastroesophageal reflux disease (GERD)	24	60.0%	
Diabetes	6	15.0%	
Thyroid	13	32.5%	
Osteoporosis	17	42.5%	
Non-ambulatory	22	55.0%	
Pneumonia in past year	9	22.5%	
Epilepsy	27	67.5%	
Dementia	0	0.0%	
Axis I diagnosis	18	45.0%	
Co-morbid conditions			4.7 (1.9)
<i>None</i>	0	0.0%	
<i>1-2</i>	6	15.0%	
<i>3+</i>	34	85.0%	

Table 5. *Risk scores and nursing levels for people not in ICF or SNF (N= 40).*

Variable (range)	Mean (SD)
HRS	
<i>Continuous scores</i>	31.13 (13.97)
<i>Categorical scores (1-3)</i>	2.48 (0.72)
SGS categorical scores* (1-3)	2.50 (0.75)
PNMS categorical scores* (1-3)	2.50 (0.64)
Overall risk level (3-9)	7.48 (1.81)
Nursing level (1-3)	1.95 (0.93)

*\*Mean and standard deviation (SD) for SGS and PNMS continuous scores cannot be computed since individuals who are non-ambulatory and those who are on enteral feeding, respectively, automatically receive high scores (see text for details).*

Table 6. *Dual diagnosis and nursing level (N= 40).*

		Yes	No	Total
Nursing level 2 or 3	Yes	9	13	22
	No	9	9	18
	Total	18	22	40

Table 7. *Daily rates in dollars (N= 40).*

Mean ± SD	453.40 ± 146.28
Median	506.93
Skewness	-0.55
Minimum	142.25
Maximum	690.00

**Figures**

Figure 1. Age vs. HRS.  $r = 0.293$ ;  $p = 0.023$ ; green line represents the correlation line

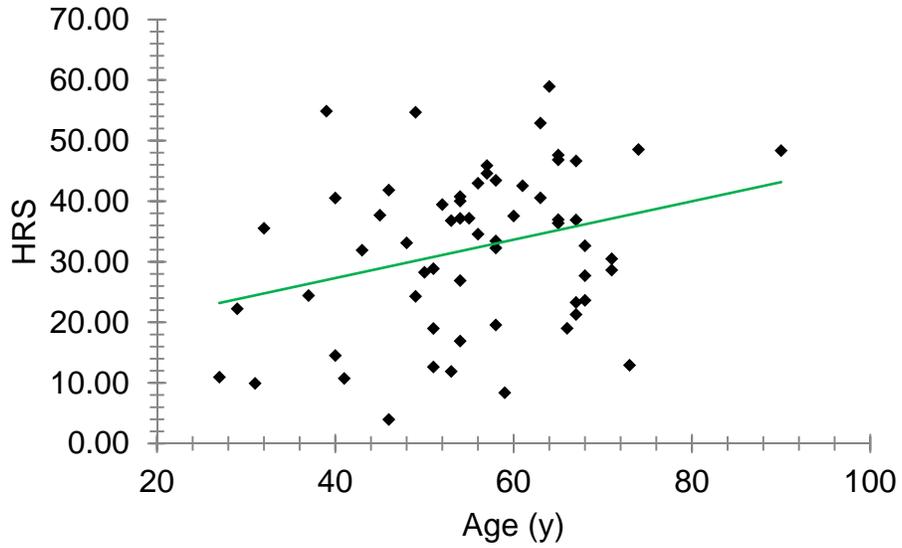


Figure 2. Risk scores 2012 vs. 2011. Mean and standard deviations are indicated in white on each bar; \*indicates statistical significance; NS= not significant

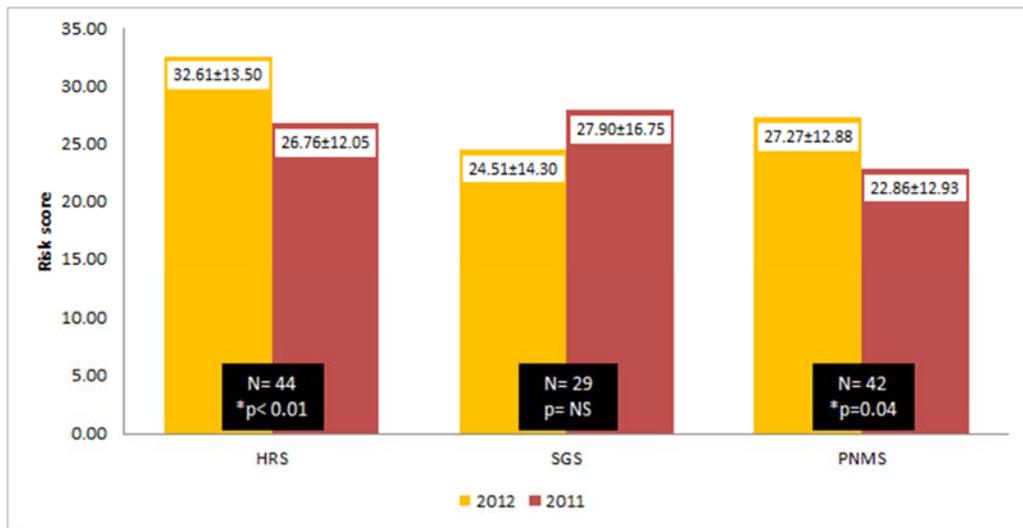


Figure 3. *Box plot of overall health risk scores distribution (N= 40). Note the negative skewness (-0.79) of the distribution.*

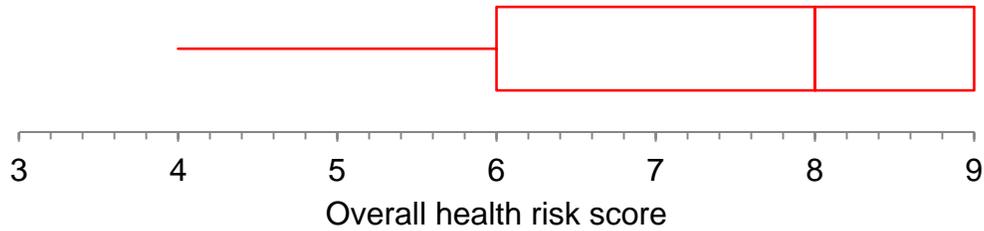


Figure 4. *Box plot of nursing levels distribution (see text for details). Median (2) and mean (1.95) almost overlap.*

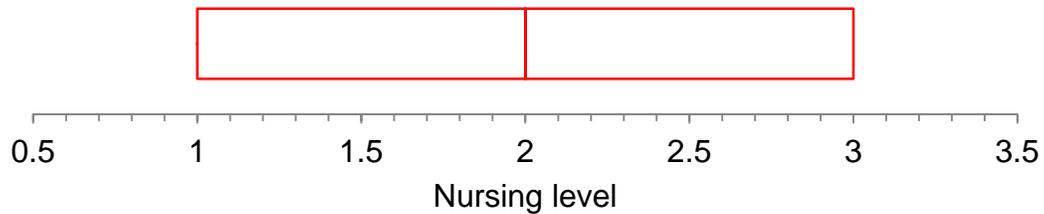


Figure 5. Nursing support levels vs. overall health risk scores.  $r = 0.21$ ;  $p = 0.19$ .

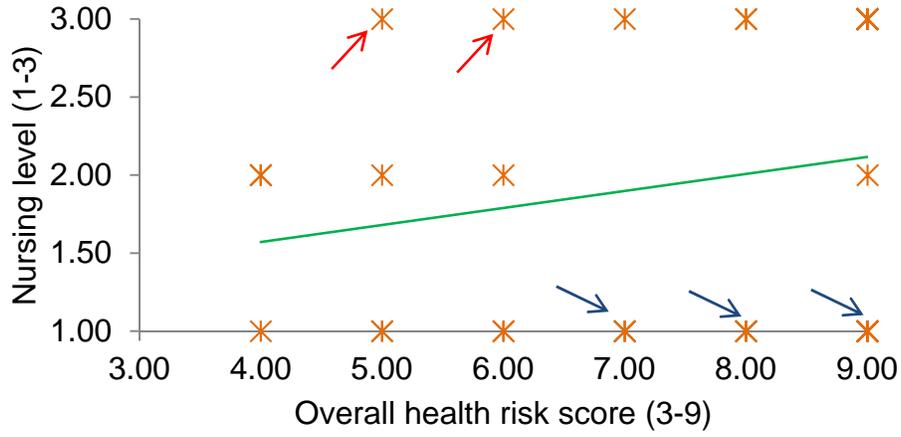


Figure 6. Nursing support levels vs. HRS (N= 40).

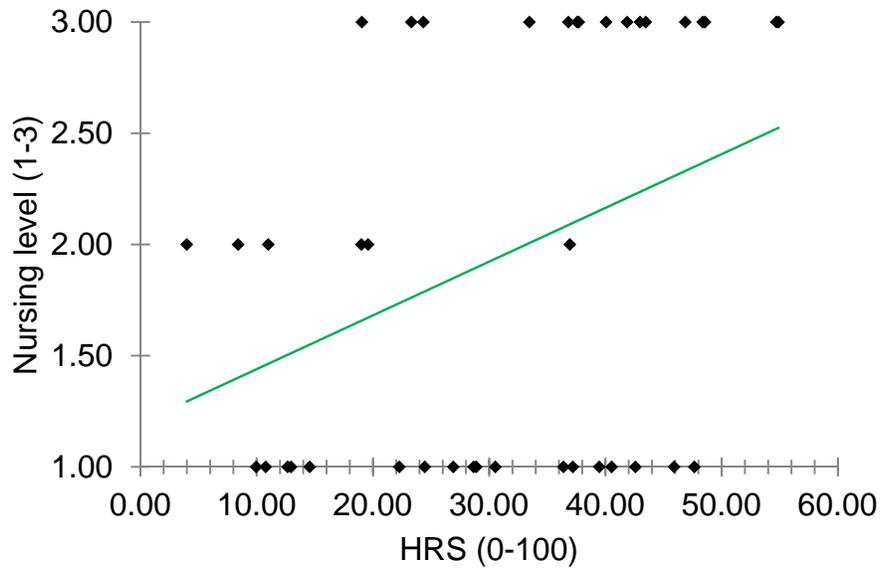


Figure 7. Nursing level vs. health priority rank (N= 40).

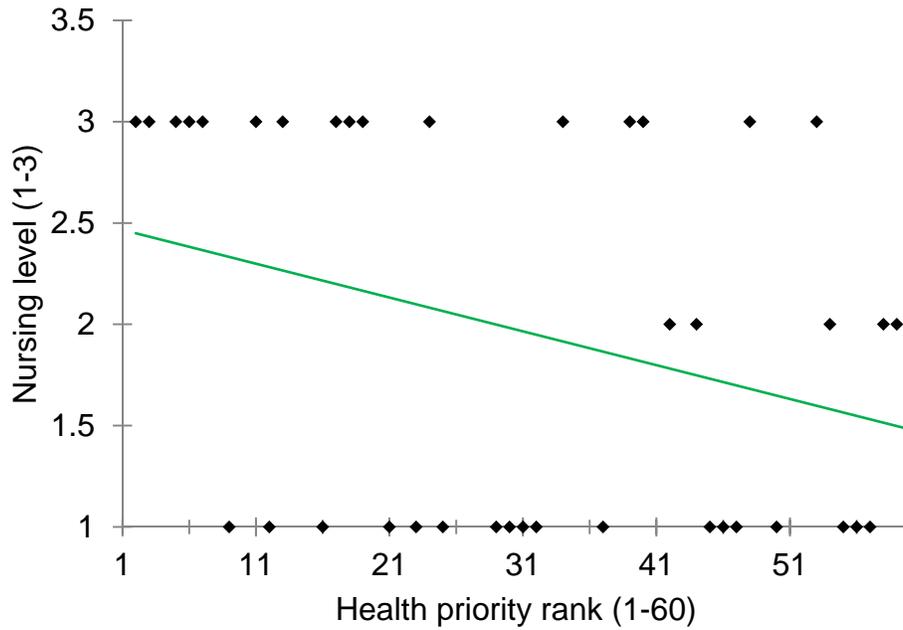


Figure 8. *Nursing level vs. daily rates (\$)*. See text for details.

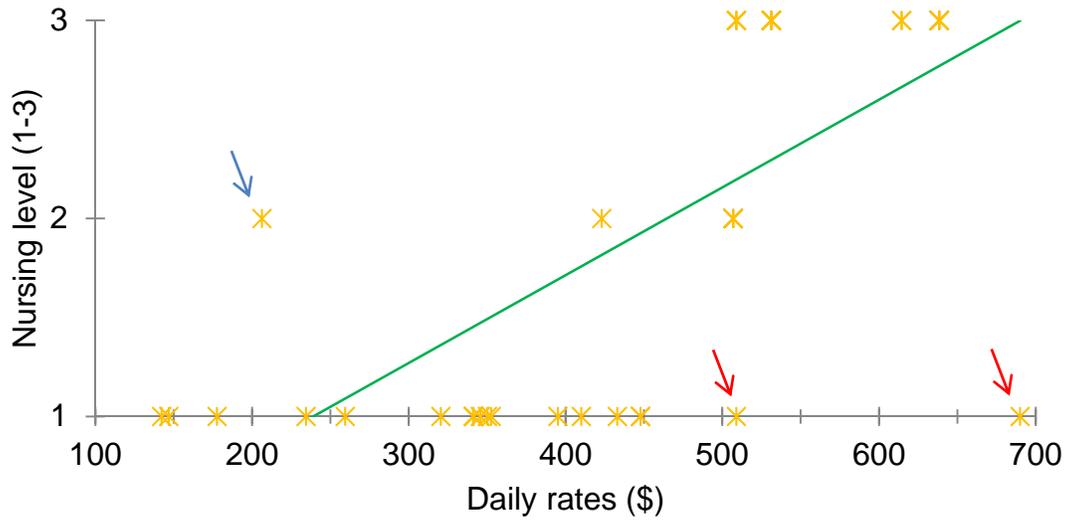


Figure 9. *Distribution of daily rates*.

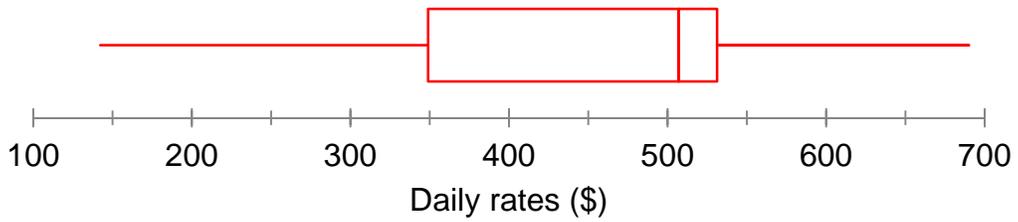


Figure 10. *Daily rates (\$) vs. overall health risk scores.*

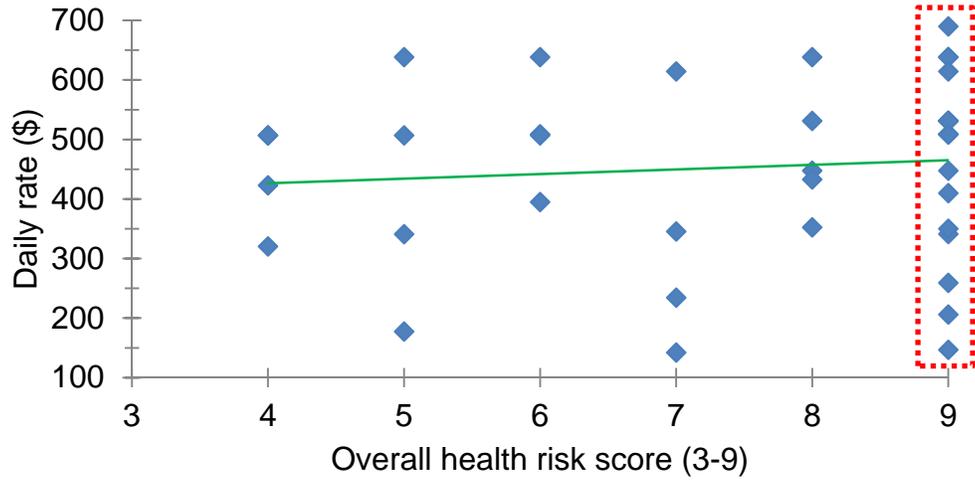


Figure 11. *Daily rates vs. dual diagnosis.*

