# Creating inclusive health systems for people with intellectual disabilities: An international study

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**Abstract**

**Background:** Creating equitable access to mainstream health and healthcare service has been promoted as a means of addressing the health disparities experienced by people with intellectual disabilities (ID) globally. **Specific** **Aims:** This study addressed two questions: What strategic actions are most likely to bring about inclusive primary, secondary and tertiary health systems for people ID? What are the system indicators that can be used to evidence a reduction in health disparities for this population? **Method:** A four-phase study was undertaken involving an international expert advisory group, literature reviews and individual interviews with 16 key informants from Special Olympics (SO). These led to an online international survey in which 61 respondents rated the relevance and feasibility of 30 strategic actions and system indicators to promote inclusive systems and reduce health disparities. **Findings:** All the strategic actions and system indicators were endorsed as relevant but less so for the feasibility of implementing them. Top-rated strategic actions included the availability of policy statements and practice guidelines on making reasonable adjustments, mandatory training of health professionals on ID and their involvement as co-trainers in staff training. **Discussion:** Implementing these strategic actions and system indicators will be a major undertaking and one that is unlikely to be speedily achieved given the many different policy and health systems that exist even within a locality as well as nationally and internationally. Nonetheless the identified actions and indicators from this study can form the basis for improved access to health and for advancing the human rights of persons with ID.

# Introduction

The poorer health experienced by people with intellectual disability (ID) is well documented internationally (World Health Organisation, 2011: Taggart & Cousins, 2014). Moreover, a recent systematic review of early deaths and causes of death reported that people with ID have higher mortality rates, and died earlier, compared to their non-disabled peers (O'Leary, Cooper & Hughes‐McCormack, 2018). This evidence has been reported internationally: in Australia (Florio & Troller, 2015): Canada (Stankiewicz et al., 2018); England (Heslop & Glover, 2015); Finland (Arvio et al., 2016); Ireland (McCarron et al., 2015) and the USA (Lauer & McCallion, 2015). The leading causes of death for this population include respiratory disease (Heslop et al., 2013), cardio-vascular disease (Janson et al., 2013) and certain cancers (stomach, colorectal, oesophagus cancer) (Glover et al., 2017; O’Leary et al., 2018). Robertson & Hatton (2019) highlighted there were significant gender differences in the mortality patterns of people with ID when compared to the non-disabled population, with younger females with ID more likely to die early.

There is also growing evidence of the poorer physical and mental health experienced by people with ID internationally. They have higher rates of epilepsy (Robertson et al., 2015); Type 2 diabetes (MacRea et al., 2014); osteoporosis (Balogh et al., 2017) and dementia (Axmon et al., 2017; Strydom et al., 2009). Although most of the evidence comes from more affluent countries with well-developed public health systems, the risk of poorer health is probably even greater in low and middle-income countries (Emerson & Savage, 2017; O'Leary, Cooper & Hughes‐McCormack, 2018 ).

Some of the poorer health of this population may result from biological impairments associated with the person’s disability (e.g. physical and sensory impairments, epilepsy, and early onset dementia) (Taggart & Cousins, 2014). However, other lifestyle factors (i.e. diets, sedentary behaviour, physical activity, and anti-psychotic medication) are also implicated along with a lack of timely access to effective healthcare and preventive actions, as well as the impact of wider social determinants of health (notably prejudicial attitudes, discriminatory practices and poverty). The resulting health inequities or disparities experienced by people with ID are now well acknowledged, namely "*differences in health outcomes at the population level, that …are linked to a history of social, economic, or environmental disadvantages, and that these differences are regarded as avoidable*” (Krahn, Walker& Correa-De-Araujo, 2015:p.S198).

A major goal of public health is to reduce health disparities within populations because of the social and economic benefits it brings (World Health Organisation, 2008). The recent UN Sustainable Development Goal relating to health is to *“ensure healthy lives and improve well-being for all and for all ages*”. And more particularly: “*to achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.*” (United Nations, 2018).

For people with ID, a major cause of health disparities seems to be their poorer access to mainstream healthcare, health promotion and disease prevention (Emerson & Baines, 2011; Krahn & Fox, 2014). While personal characteristics such as poor communication skills, transport difficulties and poverty undoubtedly contribute to this population’s lack of access to health, another significant reason in many countries is a failure in health systems to make reasonable adjustments to accommodate persons with ID and their specific health needs (Ali, Scior, Ratti, Strydom, King & Hassiotis, 2014). The consequence is that people with ID are excluded from the services, supports and communities that will promote their health, wellbeing and quality of life. Similar exclusions occur from other public services, notably education, but there is a growing body of knowledge as to how such systems can become more inclusive (Ainscow, 2016). It was against this background that the present study was conceived. The primary aim was to identify the strategic actions that health systems should take to become more inclusive of persons with ID.

**The context for the study**

Special Olympics (SO) is a world-wide sports organisation for people with ID. Now in its 51st year, it is active in 174 countries with over 5 million athletes and nearly half a million coaches involved in regular training sessions (<http://annualreport.specialolympics.org/reach-report>).

In 1997, Special Olympics instituted a Healthy Athletes program which offered free health screenings and education for participants in local, national, regional and international competitions. To date, Special Olympics has conducted over two million athlete screenings world-wide (<https://www.specialolympics.org/our-work/inclusive-health>). Through local partners, remedial action is provided at the screenings for some of the identified health needs, such as health promotion, dental treatments or the provision of glasses. However for many conditions, an onward referral to continuing healthcare services has to be made. In order to facilitate better follow-up care and also encourage year-round health and wellness, Special Olympics launched their Healthy Communities program in 2012. Currently Special Olympics works through a global network of 225 Special Olympics Programs, which are independent, accredited 501(c)3 organizations that operate under the General Rules of Special Olympics. Each program could bid for funding to instigate a ‘Healthy Communities’ project, the aim of which was to improve access to quality healthcare and preventative health education for people with ID, primarily through strengthening the capacity of existing healthcare and prevention systems. Healthy Community staff work with local and national partners including healthcare and wellness professionals, universities, NGOs and government officials.

In 2016, Special Olympics launched a new health strategy aimed at creating a tipping point for the inclusive health of all people with ID. The aim is for people with ID to be included in all mainstream health policies and laws, programming and services, staff training programs and education, communities and funding streams. To achieve this goal, Special Olympics identified two primary questions for this study. First, what strategic actions are most likely to bring about inclusive health systems; whether it be at a local or national level and provided by either statutory or non-governmental agencies? Second, what are the indicators that can be used to evidence a reduction in health disparities for people with IDD; within local as well as national populations?

**Research Strategy**

A four phase study was undertaken.

**Phase 1:** An advisory group of six persons (see acknowledgements) was identified who together with the two project leaders (RMcC & LT) embodied a range of international expertise in research, health policy, service delivery and family care. The advisory group identified relevant literature and advised on possible strategic actions and system indicators. They critically reviewed and quality assured all other phases of work.

**Phase 2:** A scoping literature review was undertaken by the first two authors with a discrete focus on identifying strategic actions and indicators of inclusive systems that had been proposed mostly in review papers. From this, a socio-ecological conceptual framework emerged (see Figure 1). A listing was also made of the possible strategic actions and system indicators that previous studies suggested would make health systems more inclusive.

*Insert Figure 1 about here*

The current literature suggests that access to health services by people with ID was primarily studied at a locality or community level – be it primary, secondary or tertiary level care. Moreover, strategic actions are required to overcome barriers to access that are currently experienced in community settings, but information about the extent of disparities is needed to both justify the need for action as well as evidencing the impact they have on the health and wellbeing of people with ID. However in many instances actions may have to be taken nationally in order for change to happen in local services. Moreover trans-national organisations, notably the World Health Organisation and in this instance, Special Olympics, can also have an important influence. As the figure shows, strategic actions and indicators of disparities could be applied nationally and transnationally.

**Phase 3:** Individual interviews, mainly by Skype, were undertaken with 16 nominated Special Olympics staff involved with health programming in Special Olympics headquarters as well as Regional Managers and country managers for local Special Olympics Programs implementing health activities. The interviews drew on their experiences of the health needs of people with ID nationally and internationally, the strategies they had found effective in health improvement, and the types and means of obtaining information relating to health systems and health disparities. Their responses helped to amplify the conceptual model and confirmed the possible strategic actions and system indicatorsthat were used in the next phase (see Tables 2 and 3 for examples). (Further details of the above phases are available on request).

**Phase 4:** From Phases 2 and 3, a list of 19 strategic actions relating to service policies and procedures, and a further 11 indicators of health disparities was created and validated with the Advisory Group and through further consultations with Special Olympic respondents (see Tables 2 and 3). These items formed the basis of the survey which the remainder of the paper describes with the aim of establishing consensus on the strategic actions and system indicatorsthat were most relevant to the creation of inclusive health systems. This phase was modelled on previous surveys with expert panels (e.g. Tomlinson, Yasamy, Emerson, Officer, Richler & Saxena, 2014).

**Method**

**Participants**

Two panels of informants were recruited through emails sent to three groups. One panel was drawn from Special Olympics (SO) staff involved in their health programming internationally; the second from health personnel involved in research, teaching and clinical practice with people with ID (recruited through the Health Special Interest Research Group of IASSIDD and the American Academy of Developmental Medicine and Dentistry, AADMD). An estimated 300 persons were sent the link to the online questionnaire according to information from the distributors of the emails.

In all, 61 completed responses were received (a response rate of around 20%) and Table 1 summarises the characteristics of respondents. Health professionals came from the following disciplines: medical doctors, dentists, therapists, nurses, pharmacy, dietitian, audiology, optometry, social work, sports scientist and researchers. Special Olympics respondents included Healthy Athletes and Healthy Communities personnel from most Special Olympic regions along with some family relatives of athletes.

*Insert Table 1 about here*

**Procedure**

An online self-completion questionnaire using Qualtrics software (https://www.qualtrics.com/uk/) was developed. The 19 items describing strategic actions were grouped together in one section and those relating to the 11 indicators into a further section. The items were presented singly and the panel members were invited to rate the item in terms of its ***relevance*** for making health systems more inclusive of people with ID, and also in terms of the ***feasibility*** of implementing this action.

A 10 point scale was used, in which 10 means very relevant/very feasible – through to 1 which indicates no relevance to people with ID or it is not feasible to reliably obtain this information.   As a further aid to respondents, it was suggested that ratings of 8 to 10 would suggest the item is highly suitable as a strategic action or indicator of inclusive systems; ratings 4 through 7 are indicators that the actions or indicators might be suitable pending refinements or in certain contexts; and ratings 1 to 3 were actions or indicators and that are unlikely to be suitable.

Respondents were asked to keep in mind the following considerations when rating the relevance of the items.

* The item reflects an issue that commonly effects people with ID globally and has the potential to improve the quality of their lives.
* The issue is one on which there are marked inequalities or disparities between people with ID and their peers without disabilities.
* The issue is one on which strategic and operational improvements can be achieved mainly by using available resources or easily implemented strategies.
* The indicator is, or could be especially persuasive in supporting system change.

With regard to feasibility ratings, it was suggested that respondents should take account of the resources and efforts involved in implementing the indicators of health disparities.   Thus a rating of ‘10’ is an action that could be readily implemented with relatively little extra resource or effort, through to ‘1’ which means that reliable information across systems would be very difficult to obtain. The respondents were asked to keep in mind the following considerations when rating the feasibility of obtaining reliable information about health disparities.

* Could the information be obtained from publically available data sets to provide a comparison with the general population?
* Could the information can be cross-checked from different sources?
* Is there a lower risk of the information being unavailable, biased or inaccurate?

**Ethical Opinion**

Advice was sought on ethical approval. A formal ethical opinion was not deemed to be necessary as the study did not involve personal information nor any intervention. Nonetheless, good practice was followed: participants could freely choose to participate in the study and withdraw at any time. Assurances of confidentiality were given. Members of the advisory board approved arrangements for recruitment, the study information sheet and the questionnaire itself. A response to the questionnaire was taken to imply consent to participate. Benefits in new knowledge was predicted to outweigh any inconvenience associated with questionnaire completion.

**Data analysis**

The ratings given for each item in terms of relevance and feasibility were downloaded from Qualtrics as a SPSS datafile. The median and range scores were calculated for each item on both sets of ratings. For each item, non-parametric tests were used to determine if there were any statistically significant differences in the relevance ratings given by Special Olympic (SO) personnel (including those who noted they were also health professionals) and non-SO personnel but who were health professionals) (n=40 v n=18 respectively).

Similarly differences in ratings given by respondents based in high income countries were compared with those from middle and low-income countries (n=29 v n=28 respectively). Because of the large number of comparisons that were made, the probability level was set at p<0.01 to minimise the possibility that the difference arose from chance variations.

**Findings**

*Insert Tables 2 and 3 about here*

Tables 2 and 3 summarise the median and range scores for relevance and feasibility for the 30 items rated by the 61 respondents. These are ordered by the items with the highest median score for relevance. Items with equivalent relevance ratings were then ordered by those deemed most feasible to implement.

All the strategic actions and system indicators were endorsed as relevant but less so for the feasibility of implementing them. Top-rated strategic actions included the availability of policy statements and practice guidelines on making reasonable adjustments, mandatory training of health professionals on ID and the involvement of people with ID as co-trainers in staff training. The other actions and indicators noted in the tables could of course become more significant in particular contexts or when addressing the specific health needs of people with ID.

In addition, four general conclusions can be drawn from these ratings. First, all the actions and indicators had median scores for relevance of 8 or above which had been indicated as being highly suitable in creating an inclusive health system. This finding is not surprising given the process that was followed in identifying the actions and indicators that were included in the survey but it is helpful confirmation across a variety of respondents; most of whom were active practitioners.

Second, ratings for relevance were nearly always significantly higher than they were for feasibility. In the main, we had indicated that the information would come from publically available data and understandably, respondents had reservations about the feasibility of collecting and accessing such information when it may not even be available nationally for the general population.

Third, the range scores on nearly all items were very wide which means that there was great variation among the respondents as to what they considered to be relevant and feasible. This finding is not unexpected if respondents have in mind the variations in health issues faced by people with ID, the culture and health systems they work and the respondents’ own particular health interests and knowledge. Country-specific surveys or ones focussed on particular health disciplines, might find greater unanimity in responses.

Fourth, the relevance ratings had a fair degree of agreement across respondents based in high, middle and low income countries as well as across health professionals and Special Olympics personnel. Moreover there were no significant differences on feasibility ratings among the respondents. Thus the proposed actions and indicators seem to have reasonable international applicability.

 On three of the 19 strategic actions, there were statistically significant differences (Mann-Whitney U tests p<0.01) in the ratings given by SO respondents and non-SO respondents, along with one further difference between respondents in high and lower income countries. These are shown for the pertinent items in Tables 2 and 3 and might merit further investigation in future studies.

Overall, these findings illustrate the complex, multi-faceted approach that respondents felt was required to create more inclusive health services. Nonetheless the highest rated actions focussed around training and guidance for staff alongside explicit policy and practice statements and the active engagement of people with ID within service planning and practice. Likewise information on health disparities depended on people with ID being identified in health information systems allied with having systems that capture significant health data for the general population against which comparisons can be made for people with ID.

**Discussion**

This study has identified strategic actions and system indicators that if instigated could make health systems more comprehensive and inclusive for persons with ID, and lead to reductions in the health disparities that are often reported for this population (Emerson & Hatton, 2013). Even so, these proposals may need to be embedded within broader considerations which Krahn & Fox (2014) noted should include ‘the use of data to educate decision makers, attention to social determinants and a life‐course model, and emphasis on leveraging inclusion in mainstream services where possible’ (p.431).

However implementing these strategic actions and system indicators is a major undertaking and one that is unlikely to be speedily achieved given the many different health systems that exist even within a locality as well as nationally. For example, this study did not examine whether certain system indicators are more appropriate to primary health care as opposed to tertiary care systems (Lennox, Van Driel & van Dooren, 2015: Iacono, Bigby, Unsworth, Douglas & Fitzpatrick, 2014). Experience of implementing actions in different healthcare and health promotion settings will help to make service change more effective.

Likewise these actions and indicators may need to be tailored to the various health professionals – medical doctors, nurses, therapists - as their roles can differ within and across primary care or in hospital settings. Hence, different levels of training and guidance may be needed for different disciplines albeit that there could be some commonality on issues such as adapting communication to patients with ID (Hemm, Dagnan, & Meyer, 2015).

The range of strategic actions and indicators identified here reflects the complexity of creating more inclusive health systems and public health interventions. The greater the number of actions implemented and system indicators obtained, the more likely the service could be deemed to be inclusive. Such a profiling approach would also identify improvements that services need to make in order to become more inclusive. However it is unlikely that any one system indicator is necessarily preferable to another. Rather they are interlinked. For example, in some systems the training of health professionals may require a policy commitment and practice guidelines in order for it to be implemented. Whereas in other situations, locally tailored training initiatives could foster the development of policies. There is a small, but emerging, literature that is now exploring our understanding of the context and systems that *‘can promote the integration of policies, supports and outcomes within the field of ID’* to improve the health and quality of life of this population (Claes et al., 2017; Shogren et al., 2018).

A limitation of this study is that it remains unclear whose responsibility it is to initiate inclusive actions. Leadership from managers may be a key component (Popescu & Predescu, 2016) although this may inhibit frontline staff taking the initiative, especially in low and middle income countries where hierarchical management structures tend to dominate (McConkey, 2018). However experience suggests that the stimulus for change can also come from advocacy of persons with disabilities and their family carers, assisted by organisations such as Special Olympics and their health programs (Frankena, Naaldenberg, Cardol, Linehan & van Schrojenstein Lantman-de Valk, 2015). Moreover the World Health Organisation (2017) recommends involving all stakeholders in the development of interventions aimed at improving health for all. One possible means is through a series of co-production workshops, to identify priorities and public health actions as recommended by Fritz et al. (2017) and Morton et al. (2017).

The monitoring of health disparities is another driver for health system change (Krahn, & Fox, 2014), although the paradox is that a commitment from the system towards inclusivity may be required before the system will consider gathering information in relation to possible disparities. Nonetheless our respondents agreed that a priority was the identification of persons with ID in any datasets relating to the health system in question, be it primary care records or hospital admissions (Fujiura, Rutkowski-Kmitta & Owen, 2010). One unresolved question relates to the criteria for deeming the person to have an ID: is self-declaration sufficient or does the person need to have a formal assessment and/or be in receipt of specialist services because of an ID? National agreements on this issue are vital and would be a prelude to accurate transnational comparisons (McCallion, Ferretti, Beange & McCarron, 2018).

A bigger obstacle is arguably the lack of population datasets relating to health issues, (including healthcare costs), that are of particular concern to people with ID. National census data may provide information on mortality rates and life expectancy (assuming people with ID are identified in census returns) but there may not be national coverage of other pertinent data such as health screening, medication use and immunisation (Nevill, Scott & Havercamp, 2016). Low and middle income countries in particular, often lack electronic systems of collecting and analysing health data (Mills, 2014). Hence it will not possible to evaluate the form, context or degree of inequality that may be experienced by this population. This in turn makes it challenging to fund, target and tailor health services or to monitor the health inequalities for people with ID. As the World Report on Disability (WHO, 2011) noted, a priority is the collation of better data.

This study focussed on people with ID but it is likely that these findings are applicable to other cognitively impaired populations, such as those with other developmental disabilities, brain injury or dementia, and marginalised groups within health systems and disease prevention such as immigrants (Blas et al., 2008) . It is also possible that the same or similar actions as noted here will ensure better health for all as international declarations aspire to do. Thus alliances with other disability and marginalised groups could prove mutually beneficial and lead to a better chance of instituting system change (Cacari-Stone, Wallerstein, Garcia & Minkler, 2014).

The present study had many limitations not least the paucity of research on creating inclusive health systems and the relatively small number of self-selected respondents included in the study, albeit they had an active interest and experience in addressing the health needs of people with intellectual disability. Moreover the study yielded little detail as to how the actions identified could be implemented in health systems. This is the agenda which future research and development projects must address. The value of this study is that the range of possible actions required to build inclusive healthcare has been scoped which can be applied to local, regional or national health and disease prevention systems. No longer can the excuse be used that we do not know how to make change happen.

**Conclusion**

This is the first study to explore a range of strategic actions and system indicators from an international perspective that if implemented across health systems, could lead to improvements in the health of people with ID and improve their quality of life. This paper highlights the complexity involved in targeting and changing complex health systems for a vulnerable population. Implementing the strategic actions and indicators identified in this study will be a heavy responsibility and one that will require a change in the mindset and attitude of policy makers, commissioners of services, service providers and healthcare practitioners as well as politicians and public opinion. Such dramatic shifts in complex systems are unlikely to be speedily achieved given the many different political, economic and health systems that exist within localities as well as nationally. Nevertheless a start can be made, based on the identified strategic actions and indicators recommended in this study. Further research could usefully evaluate the implementation and impact of particular actions on access to healthcare and health promotion and the resulting gains on the health and wellbeing of people with ID.

*(3,930 words)*

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**Figure 1: A conceptual model of Inclusive Health Systems**

**Table 1: Characteristics of the respondents who responded completely**

*(N=61: Note - Missing information is omitted in calculating percentages.)*

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Number** | **%** |
| **Recruited through**  | Special Olympics  | 34 | 57% |
|  | IASSIDD  | 12 | 20% |
|  | AADMD | 13 | 22% |
| **Health professional**  | Yes | 43 | 73% |
|  | No | 16 | 27% |
| **Special Olympics Involvement**  | Yes | 40 | 69% |
|  | No | 18 | 31% |
| **Gender** | Female  | 45 | 74% |
|  | Male  | 16 | 26% |
| **Age Group** | 20-39  | 20 | 33% |
|  | 40-59  | 26 | 42% |
|  | 60+  | 15 | 25% |
| **Country** | High income  | 29 | 48% |
|  | Middle | 12 | 20% |
|  | Low  | 16 | 27% |
|  | Unsure  | 3 | 5% |
| **Length time in ID**  | Median 16.5 years (range 1 to 40 years |

**Table 2: Ratings for strategic actions to promote inclusive health system**

|  |  |  |
| --- | --- | --- |
| **Actions** | **Median (range) Relevance rating** | **Median (range) Feasibility rating**  |
| Intellectual disability is a mandatory topic in the preservice training curriculum of doctors, nurses and therapists. | 10(0-10) | 8(1-10) |
| Practice guidelines are available for service personnel on adapting their practice to meet the needs of people with ID. | 9.5(2-10) | 7(1-10) |
| Practical training in intellectual disability is provided for service staff who come into contact with people with intellectual disabilities.*(Non-SO personnel had higher median relevance ratings 10 v 8: p<0.01)*  | 9(1-10) | 8(1-10) |
| The service system commits to, and promotes the rights of people with ID *(e.g. citing UN Conventions or national legislation).*  | 9(3-10) | 7(2-10) |
| Policy and Practice Statements make explicit mention of people with ID (and not just those with disabilities) and describe the accommodations they propose to make to meet their needs. | 9(2-10) | 7(2-10) |
| Feedback is sought from people with ID about their inclusion in the system and suggestions for improvements. | 9(1-10) | 7(1-10) |
| Awareness training in intellectual disability is made available to all staff who have personal contact with people with ID (e.g. administrative staff). | 9(1-10) | 7(1-10) |
| People with ID are involved as co-trainers for service staff.*(Non-SO personnel had higher median relevance ratings 10 v 7.5: p<0.01)* | 9(1-10) | 7(1-10) |
| People with ID are actively supported in making decisions: for example consenting to treatments*(Non-SO personnel had higher median relevance ratings 10 v 8: p<0.01)**Respondents in High Income had higher median relevance ratings than those in Middle & Low income countries (10 v 8: p<0.01).* | 9(1-10) | 7(1-10) |
| Reviews are used to examine unexpected deaths in people with ID as a means of improving the quality of supports and health care provided to people with ID.*(Non-SO personnel had higher median relevance ratings 10 v 8)* | 9(1-10) | 7(1-10) |
| There are system targets to improve the health of people with intellectual disability. | 9(0-10) | 7(1-10) |
| Easy-read information leaflets/DVDs are available on local health services and include details on how the needs of people with ID will be met. | 9(1-10) | 7(1-10) |
| Partnerships and alliances are established between Government, NGO’s and ID agencies based around mutual respect with the aim of improving access to services. | 9(3-10) | 6(1-10) |
| The system actively seeks out people with intellectual disability to participate in health promotion/health prevention activities.  | 9(1-10) | 6(1-10) |
| Health personnel (doctors and dentists) are re-imbursed for the extra time involved in assessing and treating people with ID. | 9(1-10) | 6(1-10) |
| Easy-read information leaflets/DVDs are available on keeping healthy. | 8(1-10) | 8(1-10) |
| Personnel with ID experience are employed in the service system as advisers to other staff who come into contact with people with intellectual disabilities. | 8(1-10) | 7(1-10) |
| Processes are in place (e.g. surveys) to monitor changes in staff attitudes towards the inclusion of people with ID and proposals sought from staff as to how inclusion could be improved. | 8(1-10) | 6(1-10) |
| Politicians and other leaders/opinion formers promote the inclusion of people with ID in society. | 8(0-10) | 6(1-10) |

**Table 3: Ratings for Indicators of Health Disparities**

|  |  |  |
| --- | --- | --- |
| **Possible indicator** | **Median (range) Relevance rating** | **Median (range) Feasibility rating** |
| People with ID are identified in the databases of the (service) population. (e.g. in national population datasets) | 9.5(1-10) | 6(1-10) |
| Mortality rates are tracked and reported publicly for people with ID compared to the General population. Changes over time are reported. | 9(1-10) | 7(1-10) |
| The life expectancy of people with ID is compared to that of the general population. Changes over time are reported. | 9(1-10) | 7(1-10) |
| The use of services by people with ID can be compared to people who are non-disabled and /or people with other forms of disability. | 9(1-10) | 6(1-10) |
| Immunisation rates for people with ID are compared to general population. Changes over time are reported. | 9(1-10) | 6(1-10) |
| Uptake of national screening programs by people with ID can be compared to general population. Changes over time are reported. | 9(1-10) | 6(1-10) |
| The health behaviours of people with ID can be compared to people who are non-disabled and /or people with other forms of disability. Changes over time are reported. | 9(1-10) | 6(1-10) |
| Prescribing and medication usage of persons with ID is compared to general population. Changes over time are reported. | 9(1-10) | 6(1-10) |
| The illness and impairments experienced by people with ID can be compared to people who are non-disabled and /or people with other forms of disability. Changes over time are reported. | 9(1-10) | 5(1-10) |
| A common identifier is available for each person with ID to enable data linkage across different datasets within systems or across systems. | 9(1-10) | 5(0-10) |
| The living conditions of people with ID can be compared to people who are non-disabled and /or people with other forms of disability. Changes over time are reported. | 8(1-10) | 5(1-10) |